

**A Comparative Study of Associations of People Living
With HIV/AIDS in Mozambique: The case of Maputo,
Manica and Zambezia provinces**

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Declaration

This thesis is entirely my own work and has not been previously submitted as a research project, dissertation, or thesis, at any other University

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January 2006

University of the Witwatersrand

Dedication

To my children Neusa Tania da Silveira Chitsonzo and Ivan Maximiano da Silveira Chitsonzo and my parents.

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I would like to thank to my supervisor Prof. Robert Thornton for his guidance during the elaboration of this thesis.

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Thanks to all members of the different associations of PLWA in Mozambique especially those located where I carried out the study in Maputo, Manica and Zambezia province.

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Abstract

This study was inspired by the need to develop awareness about what is going on in Mozambique regarding to the issue of HIV/AIDS. The research examined how and why the organizations of PLWA (People Living with HIV/AIDS) in Mozambique are emerging and developing, compared the particularities of the existing organizations of people living with HIV/AIDS in three province of this country (Maputo, Manica and Zambezia), and finally examined how they function, and interact with governmental and non- governmental institutions.

The study made use of the ethnographic method to design and generate a rapid "picture" of the social culture around this HIV community. The focus on this method provided further in-depth qualitative insights. Behavioral surveys were designed to provide rapid key data on sexual behavior, condom use and STI¹s. Together, these sources of data provided a spatial, quantitative and qualitative overview of the research.

The results from this study turned that the associations of PLWA and its members face many problems such as discrimination and stigma that is attached to the scourge. But notwithstanding these problems, these associations are showing an incredible dedication to addressing the issue of HIV/AIDS.

In the three provinces where this research was conducted it transpired that the associations of PLWHA are a new phenomenon, where the members are looking for their own space in order to tackle the problem that is being posed by HIV/AIDS.

The research reveals, furthermore, that there are no significant differences between HIV/AIDS associations in these three provinces. There are more similarities than there are differences. The associations have in common issues such as unemployment, low level of schooling, uncontrolled urbanization, prostitution, lack of resources to support their family members, etc. Other types of similarities are shaped by patterns of formation

¹ Sexual transmitted infections

of these associations which were similar, what invites one to think that may have been formed by the same people.

As combating HIV/AIDS seems an important tool in poverty eradication, Government, civil society and the media should step up its efforts of reducing discrimination and stigmatization of PLWA through information campaigns. They should also redesign the messages in the information campaigns to ensure that they achieve the targeted audience, and add messages that promote PLWA associations and the benefits of joining them.

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CHAPTER 1 - Scope of the Research

HIV 'community'

Our world today is one in which organizations are designed and created as tools that help those living with HIV/AIDS. It is one of the greatest challenges for our times. The fact that biomedicine has not been able to come up with a cure for AIDS has aggravated the association of this disease with stigma, discrimination, denial, shame, fear, silence and death.

HIV/AIDS: Acquired Immune Deficiency Syndrome (AIDS) is the result of an infection with the Human Immunodeficiency Virus (HIV). This virus attacks selected cells of the immune, nervous, and other systems impairing their proper function.

According to UNDP every 6 seconds, someone becomes HIV positive. The increasing number of people infected daily by HIV/AIDS in the world has, on the other hand, pushed people organize themselves and put into place existing structures to help to some extent people living with HIV/AIDS. (PNUD: 2004)

Mozambique has one of the highest HIV positive rates in the world. About 16, 2% of the adult population (15-49 years) is estimated to be HIV positive. There are about 500 new infections per day. About one million of people are HIV positive (MISAU: 2005).

This constitutes a large HIV community, that like others communities such as ethnic, economic, religious, found reasons to organize themselves to respond their eminent needs.

In this study, the term 'community' means first 'HIV community'; and being a member of it has different meanings in a practical sense to different people. To some it means people living with the virus, to others it means all those who are interested in HIV issues, while to others it means organizations such as PLWHAs.

PLWHAs understand their membership in terms of rendering specific services to the community or giving financial, moral or intellectual support.

Aims of the research

The aim of this thesis is to examine how and why the organizations of PLWA in Mozambique are emerging and developing, compares the particularities of the existing organizations of people living with HIV/AIDS in three province of this country (Maputo, Manica and Zambezia), and understand how they function and interact with the governmental and non- governmental institutions. The present study also seeks to document the impact of the disease on people relationships, by looking at how the subjects of the study interact with other socio-cultural organizations such as families in their lives. Another important aim of the study is to map the experiences of the associations in the three provinces studied, as a way to understand the subjects' experiences (those living with HIV-AIDS into the associations) in Mozambique.

In short, this thesis seeks to show how the subjects of the study battle with HIV and difficulties inherent in this struggle through the associations that support them. It is in this context that author seeks to give voice to those people who have been marginalized by their HIV status and stigmatization.

Research questions

In support of the research aims formulated in the paragraph 1.2, the following research questions will be researched.

- How and why the organizations of PLWA in Mozambique are emerging and developing?
- What are the similarities and differences among organizations of people living with HIV/AIDS in the provinces of this Maputo, Manica and Zambezia?
- How do these organizations function and interact with the governmental and non-governmental institutions?

- What is the impact of HIV/AIDS on people relationships, concerning to how the subjects of the study interact with other socio-cultural organizations such as families in their lives?
- What are the experiences of the associations in the three provinces studied, concerning to dealing with people living with HIV-AIDS in Mozambique?
- How do the subjects of the study battle with HIV and difficulties inherent in this struggle through the associations that support them?

Benefits

If readers and researchers explore the nature of research questions fully:

- The research project has more chance of fitting in smoothly with the plans of this association;
- Other associations and researchers are likely to learn from the process as well as the outcomes of research projects; and
- These associations, the government and researchers will be able to consider the implications of research for practice over a longer period.

Theoretical Framework

The topic of this thesis concerns organizations of people living with HIV/AIDS in Mozambique. This topic could be viewed within the framework of “civil society” which could be complemented by the others concepts such as social movements. Considering that this study was been done in Mozambique where the PLWA associations fall in the category of NGOs, the concept of NGOs will be also discussed.

Controversially, it has been observed that there are several conceptual definitions of civil society. Which entities what should be considered as civil society and its relation to the state? This concept is contested. Social scientists too have a problem defining civil

society in a precise and concise manner. The concept has attracted different perception and meaning. In other words, there is no consensus on the exact meaning of the term. In this study the Kaviraj's definition can fit well, when he argues that civil society is "an organized institution standing outside the state's legal *jurisdiction*, which undertakes and finds a response to specific matters within the social, political economic domains". (Kaviraj *et al*, 2001). In this perspective, different kinds of organized groups of people such as associations can fall in this category.

This concept of civil society can be reinforced by embracing the another key concept, that of Social Movement, understood as a collective action, made by an informal group(s) of people of different social categories usually excluded from history who begin asserting themselves as historical actors. Normally they are committed to broad change at the levels of individual behavior, social institutions and structures. Examples include social movements of women, ecologists, gays and others which have played a role played in social and political changes through the world.

In this regard the HIV/AIDS community can be seen in the category of excluded group considering the deep stigma and discrimination associated with this disease.

Altman argues that according to the level of organizations and commitment these movements can achieve important goals. He took the example of a gay movement that managed to influence governments and the society to develop a sense of identity among its members. (Altman, 1989:30).

The organizations of PLWHA in Mozambique can be regarded as a way of responding to specific matters of concern in the world by a group of NGOs (NGO is an acronym for non-governmental organizations that cover a whole range of organizations from e.g. small local environmental pressure groups to large international human rights organizations).

- They must be non-violent groups.
- They must not want to replace the incumbent government- they should not be political parties or opposition groups.

- They should support the aims of the organizations which recognize them (Berg, 1998: 12).

The movements of civil society play an important role in the fight against HIV/AIDS. However, attention should be given to the fact that a civil society is not above in this battle. In Uganda, for instance, they work side by side with governmental institutions. The country's authority calls for full involvement of CBOs, NGOs, donors and religious institutions (Thornton, 2003a; 2003b).

Controversially, in South Africa, the civil society, in the context of HIV/AIDS, appears to be an opposition force to the government, and puts pressure on the government to force it to pay more attention to this concern. In Mozambique civil society pleads with the government and complements the work of the government.

Using this theoretical framework, I will analyze, examine and assess their effectiveness of the role of these organizations in the context of Mozambican civil society.

Given the wide spread of HIV/AIDS in the world, and Africa in particular, the number of organizations dealing with this pandemic especially associations of people living with HIV/AIDS is increasing everyday.

This phenomenon, which opens ways for '*groups directly affected to organize themselves*' (Goss *et al*, 1995: 6), can in some way be justified by the relatively limited government intervention. The UN's secretary general, Kofi Anan assumed this same position during an interview with the BBC News answering to the question on whether he was winning the battle against HIV/AIDS, his response was that: "*I am not winning the war because I don't think the leaders of the world are engaged enough*" (in <http://www.news.bbc.co.uk/2/hit/Africa/3244564>).

People living with HIV/AIDS seek to organize themselves in associations as a way of sharing their difficulties, fighting against common enemies, giving each other emotional and spiritual support and practical assistance (Kaleeba *et al*, 2000). That is why the author personally found it important to undertake this study and see to what extent the existing three associations of PLWHA in Mozambique follow the objectives above.

Mozambique has got three PLWHA organizations so far. In mid 1990's the first one was created in Maputo city. A few years later, two other associations emerged in Chimoio city (Manica province bordering with Zimbabwe and in Quelimane city (the Zambezia central province), respectively (MONASO²: 1999). These associations operate only in the province's capital cities.

As a Mozambican, I have interest in undertaking this case study because in Mozambique, according to available reports, stands among the sub-Saharan countries with the highest number of people infected by HIV/AIDS. However, the number of associations of people living with this infection in the country is assumed to be far less than expected; in addition to this, most people likely prefer not to adhere to those associations, or even to be aware of the advantages of being a member. The fear of being discriminated and stigmatized by the society could be the most important reason.

This study will assess the importance of these organizations dealing with PLWHA.

Methods and techniques

This study was undertaken following a *qualitative ethnographic methodology*. This methodology was adopted because the study is an exploratory study. It examined specific sites, comparing small groups in order to bring out perceptions of the people involved in these organizations and their major concerns, such as:

- The people's motivations for creating the organizations of PLWHA in Mozambique
- The functioning or organizational structure PLWHA organizations
- The organizations funding sources, and
- Their major constraints

² MONASO is a network of HIV/AIDS organizations in Mozambique. It incorporates all sorts of organizations dealing with HIV/AIDS.

The study brings together the perceptions of the people involved in these organizations and their major concerns.

This research was conducted in Maputo, Chimoio and Quelimane cities in Maputo, Manica and Zambezia provinces respectively. It is in these three provinces where the first associations of people living with HIV/AIDS PLWHA were located. This specific task was to observe the way associations interact in their respective offices and/or clinics. It also gave the opportunity to look at the ways they deal with their members including their common problems.

Along side this method the research also includes the combination *semi-structured, open-ended interviews*. *Semi structured interviews* were administered to the board members of local and international NGOs as well as government institutions. *Open -ended interviews* for members of the associations and *case studies* were also recorded from some people living with HIV/AIDS in the associations.

Participant observation during fieldwork was the principal method for data collection. In short, a *multimodal approach* was an effective strategy towards strengthening the sources' reliability.

Fieldwork and procedures

The first step of the fieldwork was to make arrangements with the umbrella institutions based in Maputo which directly deal with associations of PLWHA at national level. In this way, four institutions were first contacted:

1. Rensida *Rede Nacional de Pessoas Vivendo com SIDA*, an umbrella organization that is working with associations of PLWHA.
2. MONASO, 'Mozambican Network of AIDS Service Organization' that includes national and international NGOs dealing with HIV/AIDS issues.

3. CNCS, *Conselho Nacional de Combate ao SIDA*, 'National Council on the Fight against HIV/AIDS' is a governmental institution which coordinates all activities related to HIV/AIDS at all governmental, civil society and private sector levels.
4. Ministry of Health which supervises all issues related to public health including the HIV/AIDS pandemic.

This strategy enabled me to have a picture of what these associations have been doing in the context of HIV/AIDS in Mozambique on the one hand, and to make arrangement for later contact from there with the associations and others institutions targeted for this research, on the other hand.

After this step I came to the second step of *in-depth interviews*. In Maputo I interviewed a number of the governmental institutions such as Ministry of Health, Ministry of Woman and Coordination of Welfare, Hospital dia and CNCS. All these institutions were also contacted at provincial level. All interviews were taped for transcription.

In the process, I also dealt with NGOs both national and international. One or two officers from each of them were contacted. The selection was done according to the level of involvement in HIV/AIDS issues. From HIV associations, however, I interviewed two staff members, the president or the executive director or secretary, or both of them, depending on their availability. In the provinces five members of the same associations who were targeted responded as well to the requests. The number of National and international NGOs in each province varied from one province to another. The majority of them were contacted whenever they were referred to the author by others during our interviews.

It is important to observe that this study was possible only in the capital cities of the provinces for the simple reason that the districts do not have associations of people living with HIV.

In Maputo were in total 25 interviews with HIV-AIDS positive effective members of the associations including case histories of NGOs, national and international, and five governmental institutions. Similarly, in Quelimane two interviews were conducted with

HIV associations, ten HIV positive members belonging to both existent associations. Three International and three National NGOs were contacted as well as the three most important governmental institutions at provincial level: Health, Women and coordination of Welfare and CNCS National Council on the Fight against HIV/AIDS.

In Chimoio were contacted two associations made up of twelve members, six in each association. Two international and three national NGOs were contacted. The same governmental institutions contacted in Quelimane were also visited and contacted in Chimoio.

Given the nature of the study, it was not easy for some people to respond to the interviews for fear of discrimination and stigmatization. In Maputo, for example, in one of the support group I was asked to reveal my sero status – to determine whether I was like them, since this would make them comfortable during the interview. Skhosana confirms how difficult is to conduct study in this perspective. According to her, she found specific strategies in that moment to deal with her research (Skhosana: 2001)

In Manica province I was asked by two young people to be paid for having been interviewed. It has been a practice for some researchers to pay the interviewees. However I did not pay informants for information.

Special problems arose during the fieldwork in all studied provinces when some associations (i.e. members of the board) of HIV people were the ones who decided which people should be interviewed and which not. Without their mobilization it was not possible for me to find people for those interviews.

All in all, the fieldwork covered a period of three months. It should be acknowledged that all was done successfully but not without some obstructions. I quickly learned an important lesson that a researcher even in her own country should not assume that the interviews will be transparent and unproblematic. As a field worker I was, also able to learn more than the scope of the research itself. I was able to notice laughter, reprimand, correction through which I had to see how people living with HIV socialize or fail to socialize with others.

Constraints

Language or communication barrier was one of the difficulties I had in the field, but not a major one. In cities where most people speak Portuguese, I chose Portuguese as a language for communication. However, some HIV positive were more confident speaking in their native languages, I solved the problems through interpreters.

Photographs were taken to document some findings and they added support to the data collected. Verbal consent of participants was sought before photographs were taken. Some of the informants did not allow pictures, fearing that I could sell their images.

Ethical considerations

Given its delicacy, this research topic has a lot to do with informant's intimate life and privacy. Interviews were conducted in a careful manner, following the principles of respect and confidentiality according to the WITS University's statement of principles and the American Anthropological Association's statement of Ethical principles for Anthropology. I made our informants aware of the research's purpose, which is to seek and contribute to further improvement of the associations of PLWHV and their memberships and obtained verbal or implicit consent. In learning about others through active participation in all steps of my fieldwork, I learned for example, in this context of HIV, those who were suffering from it, I tried by all means to make them feel free and more comfortable despite their status. I also protected their identity as professionally required for an anthropologist researcher. In short, respect and confidentiality were the most important requirements considered during the fieldwork.

Structure of the work

In **Chapter I** of this work, a brief overview of the topic is outlined. The Introduction identifies also the scope of the study of PLWHA 'People Living with AIDS'. The concept of civil society and social movements are discussed. The principal techniques used in the research, are described.

Chapter II gives a broad picture of HIV/AIDS in Mozambique. After years of colonial rule, civil war, floods and famine, Mozambique is now considered one of the world's poorest countries with one of the highest HIV infection rates – 13.6% of 15-49 year olds are HIV positive. This chapter gives a picture of PLWHA organizations in fighting against HIV/AIDS and helping HIV people.

The literature review is the main concern of **Chapter III**. This section provides the sources cited throughout the work. It offers information on the range of other studies cited and how they influence this work. I include work of scientists in other disciplines, such as bio-medical, psychology, and culture. The literature cited in this section shows how HIV/AIDS issue is the concern of everybody and not just anthropologists.

Chapter IV is about presentation of the three provinces in study. The general idea of these provinces related to the location in the country as well as the population is given. Some socio- economic indicators are shown in the context of specificities of each provinces. Factors that would influence the prevalence of HIV/AIDS are presented. On the end there is presented the PLWA organizations in each province and a brief history of their creation and function.

Chapter V deals with the presentation and analysis of results. This results section contains the **data** collected during experimentation. It is the heart of this paper. In this section, much of the important information is in the form of translated interviews. Tables and graphs of characterization of members of the associations of PLWA are also given.

The **Conclusion VI** re-states clearly and concisely the key issues covered in each of the main points in the body of the text, and provide a concluding statement that integrates the ideas presented there.

CHAPTER 2- BACKGROUND INFORMATION ON HIV/AIDS IN MOZAMBIQUE

Country profile



Mozambique



Fig. 1 Map of Mozambique country
([http // www.worldpress.org/ profiles/ Mozambique](http://www.worldpress.org/profiles/Mozambique))

The population of this country is approximately 18 million people where more than 99% belong to indigenous ethnic groups. The ratio of men to women is 96 to 100. Forty-two percent of the population is under the age of 15. (INE: 2000)

Mozambique is considered one of the world's poorest countries, and all of the country's social indicators are well below sub-Saharan African averages. Mozambique's ten-year civil war reversed post independence improvements in basic services and had a major impact on mortality and morbidity, especially among children. Thirty to forty percent of Mozambique's children are chronically malnourished. Roughly 60 percent of the population still lack access to health services. The Mozambican government now allocates 8 percent of its current budget—about US\$2 per person per year—to the health sector. (INE: 2000)

During most of the civil war, the government was unable to exercise effective control outside of urban areas, many of which were cut off from the capital. An estimated 1 million Mozambicans perished during the civil war, 1.7 million took refuge in neighboring states, and several million more were internally displaced. In the third FRELIMO party congress in 1983, President Samora Machel conceded the failure of socialism and the need for major political and economic reforms.

In December 2004, Mozambique underwent a delicate transition as Joaquim Chissano stepped down after 18 years in office. His newly elected successor, Armando Emilio Guebuza, has promised to continue the sound economic policies that have encouraged foreign investment.

Part of the poor conditions in Mozambique is a heritage of Portuguese colonization, because under this regime, educational opportunities for black Mozambicans were limited, and 93% of that population was illiterate. In fact, most of today's political leaders were educated in missionary schools. After independence, the government placed a high priority on expanding education, which reduced the illiteracy rate to about two-thirds as

primary school enrollment increased. Unfortunately, in recent years school construction and teacher training enrollments have not kept up with population increases. With post-war enrollments reaching all-time highs, the quality of education has suffered. However this has improved after independence (Serra: 2000).

HIV/AIDS in Mozambique

HIV/AIDS is one of the greatest threats to the development of Mozambique, kills people in their productive and reproductive years. This pandemic has a responsibility to increase the vulnerability of the families associated with the increasing of numbers of orphans in the country. Health and education services are losing skilled staff, reducing the provision of these services.

According to the MISAU, Ministry of Health and the INE the epidemic situation of HIV/AIDS in Mozambique by province and by the three regions in 2002

Province of Mozambique	Prevalence %	Prevalence %/ Region
Niassa	11.1%	8.4% North region
Cabo Delgado	7.5%	
Nampula	8.1%	
Sofala	26%	16.7% Center region
Manica ³	19%	
Tete	14.2%	
Zambezia	12.5%	
Maputo city	17.3%	14.8% South region
Maputo province	17.4%	
Gaza	16.4%	
Inhambane	8.6%	
Mozambique	13.4%	
Mozambique actually	16.2%	

Table 1 HIV Prevalence by Province. Source: MISAU: 2002 and 2005

According to MISAU pointed that in 2001 about 56.600 adult people have died by AIDS
Concerning the life expectation according to the projection, in 1999 it was 43 years; 2004 46.4 years and in 2010 could be 50.3 years without AIDS. However the life expectation

³ The provinces in red are that in study

with AIDS in Mozambique at the same periods was 41 years; 38 1 years and will be 35.9 years with AIDS, respectively. (MISAU: 2005).

For the surprise of Mozambican the recent data of Ministry of Heath indicate that the current national prevalence 2005 is 16.2 %. Half of the people living with HIV/AIDS (PLWHA) in Mozambique are between the ages of 15 and 29. Girls and women are at especially high risk and are being infected at a ratio of two to one over men. In 2004 we had 470,000 orphans due to HIV/AIDS in Mozambique. Currently, we have more than this figure, which will increase to over one million orphans by 2010. (MISAU: 2005). Extreme poverty, urban and cross-border migration, unequal distribution of power between men and women, stigma, and low literacy levels fuel the HIV/AIDS epidemic.

The first AIDS case was reported in Mozambique in 1986. The country's HIV prevalence rate is lower than the rates of neighboring Zimbabwe, Zambia and Malawi, largely due to the isolating effects of the civil war.

The scale and future impact of HIV/AIDS in Mozambique can only be understood by examining it in relation to its young population. Youth, aged 10-24, comprise 34% of Mozambique's population, and youth aged 15-24 account for 60% of new HIV infections in a country estimated to have a HIV prevalence rate of over 12% (MISAU:2005) .

Although the isolating effects of a ten-year civil war kept the HIV prevalence rate in Mozambique lower than the rates in neighboring countries, it is still one of the nine countries in Africa hardest hit by the epidemic: Given the increasing number of people suffering from HIV/AIDS the Mozambican government has approved antiretroviral therapy (ATR) and diagnostics policy in the country. But the costs due to the rising number of persons living with HI/AIDS will overwhelm an already existent health care budget. Prevention activities focused on young people, the mobile population, better quality and coverage of voluntary counseling and testing services. The actual cost of ARV treatment per patient is 250 USD per year what means that the government has to expend too much money only for this matter while malaria tuberculosis, cholera continue to kill more than AIDS (CNCS: 2005)

In short, Mozambique is a country where people have seen all. The Mozambique Liberation Front, or Frelimo, formed in 1962 by Eduardo Mondlane, Frelimo sought to completely liberate the country from Portuguese rule. The war lasted over 10 years, effectively ending in 1974 when the fascist regime was overthrown. The independent Republic of Mozambique was proclaimed on 25 June 1975:

Then troubles really began. The drought and famine of 1983 also brought the country to its knees. In January 2001, floods killed about 700 people, left half a million homeless and devastated the economy. Some of the flooded areas - and many others besides - were then hit by a drought the following year. The economy remained crippled by debt, with annual payments almost twice the public health budget. Above and overall the country is fighting against HIV/AIDS today.

NGOs and HIV/AIDS in Mozambique

The NGO sector in most countries like Mozambique led the early responses to HIV/AIDS issue. There are many different typologies and classifications of these NGOs. However we can distinguish two: national and foreigner NGOs that specifically dealing with AIDS called by AIDS services. Normally these organizations are members of MONASO and RENSIDA national umbrellas of organizations dealing with HIV/AIDS and of PLWA respectively. Since the end of decade 80 local NGOs of PLWA started emerging and integrating these two umbrellas.

These organizations in general focus their activities mainly on the following areas:

- Prevention of sexually transmitted diseases and of HIV/AIDS transmission among young people through school awareness programmes;
- Fight against discrimination, stigmatisation and marginalisation of people affected by and infected with HIV/AIDS;
- Support of families caring for relatives living with HIV/AIDS;
- Care for children orphaned by HIV/AIDS.

- Advocacy for ARV treatment
- Few of them in partnership with the government provide ARV treatment

The increasing number of PLWA members enlarged the “HIV community” that wanted to organize themselves. Similarly, the increasing disclosure of HIV- positive status has led to the formation a national network of PLWHA, as already indicated in the introduction, which works in partnership with other organizations and the government. The RENSIDA (National Network of People Living with HIV/AIDS was created in 2000.

In this Network are included PLWA but mostly who are member of HIV/AIDS associations. The most important aim of this National network is to stimulate the formation of self-help groups of local People Living with HIV/AIDS, to coordinate and support their activities, and to help bring them together in one voice. This network for PLWHA receives financial support from SAT, UNICEF, Action Aid and ONUSIDA (interview with secretary of Rensida ,2004: Maputo)

The association known as *Kindlimuka* ‘wake up’ in the local Ronga language is the oldest of the PLWHA organizations in Mozambique, founded in 1996. Based on Kindlimuka’s experience, thirteen other associations of PLWHA have been established in others provinces. The formation of these associations is behind National and Inetrnational NGOs as well as governmental institutions such as services of blood and GATVs. (services of counseling and voluntary test)

These associations have as main tasks:

- Providing counseling, home -based care and inc ome generation activities including the production and sale of clothing and material for construction.
- Organizing education on how to prevent HIV/AIDS for young people aged 13-18 years in schools. Testimonials by association members on their sero-status have become an effective tool used to reduce stigma and to increase awareness.

- Identifying vulnerable children and families caring for orphans, with involvement of community leaders.

RENSIDA is an umbrella organization. It is a Non-Governmental Organization, which integrates all organizations of People Living with HIV/AIDS in Mozambique. Activities implemented by RENSIDA with the UNICEF complement each other. UNICEF has been supporting institutional capacity building of RENSIDA through technical advice, training, and the provision of material and equipment. RENSIDA developed a national strategic plan and operational plans of the associations in 11 provinces for 2004. In addition, UNICEF has been supporting community monitoring projects for orphaned and vulnerable Children through RENSIDA in fifteen districts in Gaza (Kuvumbana), Manica, Sofala, Tete and Zambézia provinces

CHAPTER 3 - LITERATURE REVIEW

HIV/AIDS as a social phenomenon

Today, as in the past, those who write about the issue of HIV/AIDS emphasize the role of people living with HIV as infectors rather than those who are infected to such an extent that this view is widely accepted as "common sense." In public health initiatives, the "public" appears not to be concerned about how to help these people who contracted HIV to live a better life of stigma, rejection and marginalization, and also help them not to disseminate or transmit the virus to others – innocent people and children considered to be potentially innocent victims of AIDS, at the expense of others like prostitutes. But, in so doing, writers promote oppression of HIV positive people and impede the struggle against HIV.

The first cases of HIV/AIDS in the world were associated to the homosexual people and drug users so people in the heterosexual life were not concerned about this disease.

Today many people blame prostitutes or sex workers. Generally, women and men working in the sex trade have been considered as vectors for transmission rather than persons who, for many reasons, including legal reasons, are vulnerable to contracting HIV. But most recently, the evidences show that every one is susceptible to be HIV positive independently of their sexual orientation. Related to HIV/AIDS indicators in Africa, are handicapped by inadequate means of confirming diagnosis, on the other hand the high sickness rates contribute in a large way to obscuring the true prevalence of HIV/AIDS in many African countries (Agadzi, 1989: 92). HIV/AIDS cannot be seen anymore as only a bio-medical disease. "Specific social and cultural patterns such as the sexual networks, the availability of needles, the political and economic power relationship of prostitution, the nature of transport routes areas of high prevalence are factors showing the social face of this disease" (Altman, 1994).

As Altman remarks that no illness in human history has generated so many meetings, so many scientific publications, nor so much political rhetoric and government response Altman, 1994:2) as HIV/AIDS. In fact, a number of articles trace the history of

HIV/AIDS (Altman, 1994; Macks, 1987; McAdam, 1996; Agadzi, 1989; Corr, 1994; Cad & E, 2002). Though different resources have been consulted in the frame of this research, this work, however, has heavily drawn on the research conducted by Altman's *Power and Community: Organizational and Cultural Responses to AIDS*, 1994 that discusses various HIV/AIDS organizations. It shows how other forms of responses to HIV did not successfully help those who live with the virus and how, most striking of all has been the response from those most affected by the epidemic itself. It strengthens the idea that without strong community-based responses the best meaning of public health systems will fail to deal with the crisis of AIDS. For Altman "one of the major goals of the community-based movement has been to slowly drag public officials to recognition of the multi-faceted needs of an appropriate HIV/AIDS strategy.

HIV/AIDS and vulnerability of poor people

Altman recognizes that the HIV spread and its social consequences are closely linked to the dislocations of economic and social 'development' and, in West, to the growth of particular sub-cultures and regimes of sexuality. In other words, a single approach the study of this pandemic cannot help; it needs to be approached from various angles, including cultural and economic aspects. According to PNUD (2004) 39.4 million people are estimated to be living with HIV 25.4 millions can be find in Sub Saharan Africa. The increasing number of people with AIDS in Africa mainly in Southern Africa, for example, allows us to associate this disease with poverty. Obviously, the people of this region are most frequently infected because of their life conditions (Altman: 1994).

Lancet (2004) in Preventing HIV/AIDS through poverty reduction remarks that the association of poverty with increased HIV prevalence does not necessarily indicate a causal relation. But for him, explanations have been offered at several levels as to how poverty may increase susceptibility to HIV/AIDS. He has also argued that poverty increases biological susceptibility to HIV/AIDS in the same way it does many other infectious diseases. When he refers to the malnutrition, parasitosis, and lack of access to health care among the poor, suggests that these factors undermine the integrity and immunity, and increase the likelihood of having other

untreated sexually transmitted infections. All of these influences can increase susceptibility to HIV infection and progression.

Of significance in this debate is also the fact that poverty is not alone in its destruction. It is also often associated with lack of education, and illiteracy can mean that messages regarding risk and prevention are inaccessible. These authors continue to argue that even with knowledge of the risks; the cost of prevention may be prohibitively high because many poor people are unable to afford condoms. Poverty also restricts people's choices and leaves few options but to undertake high risk behaviors. It is in this context that in Lancet (2004) also identified poverty-driven labor migration and commercial sex work as activities likely to increase HIV infection.

Thus, poverty is one important factor in increasing susceptibility to HIV/AIDS, and facilitating its spread. HIV/AIDS also increases poverty, at all levels from individual to nation, through its impact on working age populations. The morbidity and mortality among this age group affects household incomes, and is a major challenge to the ability to deliver services such as education. It is important to recognize, however, that there are many other influences besides poverty acting to facilitate the spread of HIV/AIDS. Income and gender inequalities are likely to be as important as absolute poverty, as shown by the high prevalence of HIV/AIDS in countries with large inequalities. Other challenges include finding the political will to combat the epidemic, and the stigma associated with HIV/AIDS.

With respect to this debate two conclusions to be drawn from the above observations. First, since poverty plays a role in creating an environment in which individuals are particularly susceptible and vulnerable to HIV/AIDS, poverty reduction will undoubtedly be at the core of a sustainable solution to HIV/AIDS. Therefore, investment in equitable poverty reduction efforts must continue, even in the face of other pressing needs. Second, since poverty is clearly not the only factor contributing to the spread of HIV/AIDS, there is no excuse for taking a fatalistic attitude to the epidemic, in which little can be done until some utopian poverty-free ideal has been achieved. We can concur with Lancet, and others that social factors such as poverty, gender inequality and illiteracy

are closely related to HIV/AIDS increase and need to be studied deeply, reduced if we have to succeed in our fight against HIV in Africa and Mozambique in particular.

There are more studies relating HIV/AIDS to poverty specifically on household of developing countries. Desmond and Gow advance the view that the capacity of vulnerable household and communities to respond to the economic, social, and health impact of HIV/AIDS on their households are weakened ever day due to extreme poverty. women and children are the most seriously affected “ that is why anthropology has the methodological tools to study the social experiences of those who are afflicted by this disease while simultaneously keeping the humanity of those who are infected in the professional discourse on AIDS” (Desmond & Gow, 2002:19).

HIV/AIDS pandemic as already stated above required the involvement of community-based organizations because other groups which existed before these did not include those most affected by the epidemic. In Latin America people place stress on the concept of civil society and the need to strengthen it. In this work the stress is on the civil society which we believe can help organizations of people living with HI/AIDS such as PLWHA. Like Altman, we believe that the importance of intellectuals in the largest sense may help communities make sense of meanings of AIDS. Hence the emphasis on anthropological intervention in this research which puts high demands on social and cultural aspects of HIV/AIDS.

Countrywide organizations of PLWA

National Networks of People Living with HIV/AIDS worldwide are becoming more and more powerful acting on behalf of all people living with HIV/AIDS. The oldest national AIDS network organization in the world was found in the USA, in 1983. According to NAPWA, too little attention has been paid to the very real issue of meeting the prevention needs of people living with HIV/AIDS. The best strategies for preventing new HIV/AIDS infections should engage people with HIV/AIDS as partners, but it is also important to consider that people living with HIV/AIDS are extremely heterogeneous, and programs need to address the different needs of such a diverse group: Race, gender, sexual orientation, age, language, geography etc.

People Living with HIV/AIDS in the world are been organized themselves as a way to respond the epidemic rather than being blamed for the epidemic or regarded simply as its unfortunate victims. So HIV positive people have been valued as one of the society's most important assets in coping with the effects of the pandemic and preventing its further spread.

The global Network of PLWHA is a world network for and by people with HIV/AIDS. It is based in Amsterdam, Netherlands, and has a board of 12 members representing the various international regions. The overall aim of GNP is to work towards improving the quality of life of people living with HIV/AIDS. This can be achieved through the capacity building of people with HIV/AIDS.

According to Williams (1995), PLWHA associations in general, have the following objectives: (1) psychological care, (2) emotional support, (3) medical treatment and nursing, (4) information, (5) material assistance, (6) acceptance and non-discrimination. As mentioned above, the association's primary objective is to support people living with HIV/AIDS and their family members. It could be in terms of moral or economic support. Some of them provide community and home care assistance. Their membership is mostly impoverished people, thus limiting their capacity and effectiveness in advocacy. This also reflects the existing social stigmatization against them from the moment they reveal to be HIV positive or AIDS patient. This is a real situation in Mozambique. In different parts of the world, for instance in Uganda where HIV/AIDS awareness is high and greatly supported by the civil society, there are national networks of this kind of associations.

The examples of Uganda and South Africa

Organizations of PLWHA worldwide enface the problem of discrimination and stigma, but given the increasing number of infected people and this kind of associations they are fighting these issues with a relative success. This has proved true in Uganda through the TASO Organization of People Living with HIV/AIDS and NEPWA National Association of People Living with HIV/AIDS in South Africa where they have been extremely important in shaping their society's response to HIV/AIDS.

In fact, Uganda's response to HIV/AIDS has been comprehensive therefore is seen as a model for the rest of Sub-Saharan Africa. Since 1992 HIV prevalence in Uganda has dropped by more than 50%. The involvement of government institutions, the civil society as well as numerous community led initiatives could be the most important factors for decreasing HIV/AIDS in this country.

(www.cdc.gov/nchstp/od/gap/country/uganda.htm)

Organizations like TASO (The AIDS Support Organization) and Phill Lutaya initiatives strive to put a "*human face to HIV/AIDS*". So ordinary citizens associated AIDS with real people then their own risk perception increased and turn were more receptive to campaigns for safer sex. (www.aidsugand.org/pdf/role-of_vct.pdf)

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Authors like Fieldman and Carter add that successful battle against HIV/AIDS in Uganda can be also associated to the government policy strategy consisted in empowering women giving them the voice in first person. On the other the encouragement to bring out people in good status to talk about their sero positive status was helpful to combat the stigma. (Fielman & Carter, 2003).

NAPWA's international programs works to combat the HIV/AIDS epidemic by advocating for the needs of people living with HIV/AIDS and promoting the active engagement and leadership of PLWHA established partnership with other parts in the world, specially in Africa and the Caribbean countries. There are many National networks of PLWHA in the world, for example, PLWA in Australia which advocates on

behalf of people living with HIV/AIDS. This umbrella works with government researchers and pharmaceutical services. (<http://www.napwa.org.au>)

In Africa, for instance, we can take the cases of South Africa and Uganda, whereby such national networks seem to be well established. The success of South African NAPWA movement had to do with the strong experience of *civil society*. This has been able to draw on the organizational and advocacy experience of the anti-apartheid movement as well as the gay and lesbian movement. It attracted educated individuals and professionals as well as poor and marginalized people (Centre for Policy Studies, 2001: 36).

NAPWA (National association of people with AIDS) in South Africa is a non-discriminatory organization, formed in 1994 seeking to promote a safe and secure involvement that guarantees the basic Human Rights and dignity for those who are HIV positive. This organization strives to provide care and support to the membership as well as to mobilize and organize lobby and advocacy. NAPWA is, moreover, an organization whose membership is open to all people living with HIV/AIDS. Its most important programs are: mobilization, advocacy and lobbying, partnership and collaboration, gender program, organizational development and counseling and support (www.napwa.org.za).

The same structure can be found in Uganda where, because of the seriousness of the situation there, civil society, together with government, labor and business had to be strongly involved in HIV/AIDS related matters. There is an umbrella of people living with HIV/AIDS called TASO, and the 'AIDS services organization'.

The impact of these organizations even though some important achievements is still relatively limited, considering the rapid spread of the disease; Goss and Adam-Smith (1995) argue, however, that pressure groups formed by PLWHA were being represented in organizations and trying to articulate an appropriate response.

One of the most important lessons Africa has learnt in the fight against HIV/AIDS pandemic is that of '*multisectoral approach*⁴', which has proved to be a condition for successful battle. It means that all stakeholders namely government, private sector, the civil society and the media at all levels '*must come together to find ways to work against the common foe*' (Thornton 2003: 23).

HIV/AIDS and Gender Issues

"HIV/AIDS has a female face"

Worldwide in 2004 there were about 37.2 millions adult people living with HIV, of them 17.6 were women and 2.2 children (UNAIDS: 2004).

In Africa the number of women infected with HIV outnumbers infected men. Twelve point two million African women are living with HIV/AIDS as compared with 10.1 million men young African women between 15-19 are four to six times more infected than young men of the same age (Tallis, 2000:26).

Rachel Royce in Vallaers, in her article about *Awareness Is Not Enough: Gender in the HIV/AIDS Pandemic in Africa*, gives considerable ideas on the impact of gender relation and HIV/AIDS. She remarks that HIV has been called a "biologically sexist" virus by scientists, because women are in much greater danger of contracting the disease during sexual intercourse than the man. In the absence of sexually transmitted infections, a man with HIV/AIDS has an average chance of one in 500 of passing the virus to a woman in a single act of unprotected vaginal intercourse. The odds of woman-to-man transmission in the same situation are about one in 1000.

Women under the age of twenty are more likely to contract HIV because an immature genital tract has fewer layers of mucous membrane, increasing the chances that the virus enters the bloodstream. In the presence of lesions in the genital tract, the risk of contracting HIV increases up to sevenfold (Rachel Royce :2005).

⁴ This is the Ugandan approach, developed in the early 1990s.

But Women are not only at a biological disadvantage, but at a social disadvantage as well. World Health Organization (WHO), "Fact Sheet No. 242," June 2000 mentioned that "the second-class status of women in economic, social and civic life has fuelled the pandemic in much of the world." In addition, as Lesley Doyal, a Health Studies expert of Africa, pointed out that "women cannot use condoms in the way most government programs recommend. Instead they must persuade men to do so, and this can be an extremely difficult task." She further argues that in traditional African relations, women are not expected to discuss or make decisions about sexuality. Women do not have control over condom use, they also have little control over their husband's sexual practices. Women are placed at a high risk of contracting the virus, not from their own behavior, but from the behavior of men over whom they have little control.

It looks like women are victims of a patriarchal system that robs them of the freedom over their own bodies.

It is once more clear how women are disadvantaged in protecting themselves.

Following Rachel Royce in Vallaey's (2005) in a culture that places such high value on family life, and in which family size is an issue of gaining status and respect in the community, it may very well be futile to urge married couples to use condoms. In this case, not using a condom is in the best interest of the woman as well, because "in many societies, motherhood represents the only route to status, identity and personhood, and ultimately security and support in old age. As one can see, conception cannot be combined with safe sex, and most Africans want large families. Not only is the joy of having children enough reason to disregard the advice of using a condom, but there are other cultural and economic factors as well.

Given that the configuration of gender relation in Africa is associated with sexual behavior and economic security, this relation not only underlies women's particular vulnerability but also inhibit women's security and their families (Beylies: 2000). It is also believed that it is "Only when gender inequality becomes a central part of HIV/AIDS programs can we then hope to make an impact on the course of the epidemic" (Tallis, 2000: 5) So, in addition to biological and social factors, the economic situation of women in Africa also contributes to their increased endangerment of contracting HIV.

The study of rural household in Uganda has revealed that more women are dead than men. The same author remarks, however, that in countries where the majority of infected people are men, women living with HIV/AIDS are often invisible. This means that their needs are not articulated or if they are, they are not heard and not addressed ((Tallis, V., 2000: 61).

In most African countries it is women and men in the midst of their productive and reproductive lives who are most likely to become infected by HIV and die. However, given a typical age difference between partners of five to ten years, females tend to be infected at younger age. Women are infected at an earlier age. Given more rapid disease progression with age, husbands often die more quickly, leaving more widows. (Baylies: 2000:10-12).

Mozambique would not be an exception this gender issue UNAIDS also confirm that the number of women living with HIV/AIDS is growing, and women experience socio economic inequalities and discrimination, particularly aggravated with the deterioration of socio economic conditions in the country given the adoption of market economy, the makes the life waste for women concerning to access health and social services.

www.info.usaid.gov/pop-health.

African men easily forget the fact that performing sexually with many partners place them at risk of HIV/AIDS infection. This in turn has impacts on women who have little power and control in sexual interactions. Such power dynamics in heterosexual relationships raise issues in relation to HIV/AIDS that have been addressed in other

contexts, for example – sexuality, relationships access to health care, women's burden/role in health care and reproductive rights. (Tallis, 2000:60).

This is an indication of how this work cannot achieve more without addressing the issue of gender roles. It is in this regard that the International Community of Women Living With HIV/AIDS (ICW) was created in 1992 at the international AIDS conference in Amsterdam. ICW was created with a purpose to share concerns about the lack of support and dearth of information available to HIV positive women worldwide of Women Living with HIV/AIDS (WLWA) through challenging discrimination and stigma with self empowerment and self-sufficiency, dissemination of information, skill-building training research and advocacy (Artman, 1989: 25).

To return to the importance of our research regarding HIV/AIDS, let us finally remark that in discussing the issue of HIV/AIDS, safe sex and risk reduction, there is a need to take into account the way in which high risk sexual behaviour is embedded in systems of socio-cultural, economic and political exchange, particularly those systems of exchange, which typify gendered power relations between men and women. But all in all, we are enriched through this literature review to understand that HIV/AIDS needs a multiple approach rather than just a single approach

CHAPTER 4 - GENERAL OVERVIEW OF THE THREE PROVINCES IN STUDY

Introduction

The specific nature of AIDS epidemic varies from place to place, depending on historical circumstance, cultural context and contemporary political economy (...) disease is a social event, which expresses the central realities of the society in which it occurs''.(Bujura & Baylie, 2000: 25)

In the absence of a straightforward medical cure, understanding of the spread of HIV/AIDS and advice about how to intervene to limit its spread, should be largely social scientific in nature. Therefore, Social Sciences should provide the main components of the relevant knowledge-base. The very considerable regional differences of social phenomena require a particular mobilization of social science knowledge about each particular society or regional grouping of like societies.

Following this assumption this section focuses on similarities and differences in the three provinces and explains the various factors that may be behind them, in order to trace specific characteristics in the context of HIV/AIDS and its associations. It is important to speak of some economic and social factors related to HIV before speaking about HIV itself in each province. It has been observed, for example, that a high risk of HIV among people, especially adolescent is concentrated among the most socio-economically disadvantaged. There is, for example, a relationship between poverty and HIV/AIDS which includes the spatial and socio-economic distribution of HIV infection in Mozambique. That is why we will discuss HIV in each province by including social factors such as:

- geographical location;

- population mobility; and
- relevant socio cultural aspects that may be behind the HIV community in each province.

These general considerations will be followed by the story of HIV/AIDS associations in each of province.

Talking about HIV/AIDS and its associations which Altman (1994) prefers to call the Community-based organizations (CBOs), it requires first the understanding of what the term ‘community’ is all about because community is at the center of every association.

According to Altman (1994) the term ‘community’ is usually applied to a group of people defined by certain boundaries, such as race, ethnicity, religion or profession. In other words, community is defined in geographical terms; indeed, many of the central works in ‘community studies assume a geographical base to ‘community’. Others have given it a spiritual meaning, as in M.Scott Peck’s assertion that this term should be restricted to a group of individuals who have learned how to communicate honestly with each other, whose relationships go deeper than their masks of composure, and who have developed some significant commitment to ‘rejoice together, mourn together’ and ‘to delight in each other, make others’ conditions our own’ (Altman, 1994:7-8).

In light of the above perception, the author also agree with Peck’s definition of community as a group of individuals who have learned how to communicate honestly with each other and whose relationships go deeper than their masks of composure, and who have developed some significant commitment to ‘rejoice together, mourn together’ and ‘to delight in each other, make others’ conditions our own’. The author also believe that what makes these associations succeed in Mozambique is the fact that people living the same geographical space have the same culture (or belief system) and history to which they add the same sorrow imposed on them by the pandemic. All these things combined can help them to support one another and help them chart the best way forward.

But the question which still persists is what does being a member of a HIV Community mean?

Without a doubt each of these activities represents an important element that makes PLWHAs comprehensive HIV communities. If we go from the predicament that the best thing among people is the one which is the most beneficial for mankind, and that good members of the community are the ones who are productive and dynamic or the ones who care for the welfare of the Community, it is easy to deduce that PLWHAs are part of the HIV community seem to be involved more than the extent to which they personally benefit from the HIV people. They contribute for the benefit of others not looking for a reward. The above arguments give to the word community a broader context which includes both those who live with the virus and the organizations looking after them.

Maputo province

Geographical situation

Mozambique is divided into three geographical regions: south centre and north. Maputo and another two provinces (Gaza and Inhambane) constitute the south regions.

This province has as its board countries South Africa and Swaziland.

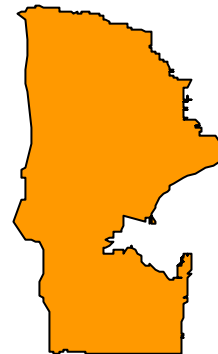


Fig.2 Map of Maputo Province

Population

In terms of population according to INE: 1997 there were 2.700 million inhabitants and the majority was concentrated in Maputo city, with about 1.800 million inhabitants. Maputo has a strong relationship with South Africa through mine labour migration since 19th century. Many people in Mozambique continue to cross the border legally or illegally looking for job in the mine areas or elsewhere like in the farms.

The International Organization of Migration (IOM, 2004) has shown that there is a straight relationship between HIV/AIDS and migration. The HIV infection is frequent in men who work far from home and live in single hostels like miners and others workers. For example there are many mine workers returning home when they are already sick-with AIDS. The risk of infecting others is in sexual relations with their partners while they are infected.

Beside all this, Maputo is part of an important corridor that links this city to Johannesburg, there are so many important roads that link this city to other country in the region such as Swaziland and South Africa from Durban. The same way that the mosquito transmits malaria and the dirty water cholera, HIV is transmitted by contact of people by travelling.

A quick look the city of Maputo clearly shows that in Maputo there is

- a confluence of people from different parts of others province who come to look for jobs or better conditions of lives;
- people from others countries embassies and international agencies are located there;
- there are the most important institutions such as universities, media, trade and enterprises;
- Important sectors of civil society are concentrated here;
- UN agencies and others international organizations, donors and most important meetings and debates about this issue are also held in this city;
- a variety of mass media that help to spread information in the different communities are also found in this city.

These aspects put Maputo in advantageous position over other provinces.

HIV/AIDS ASSOCIATIONS

By HIV/AIDS associations here the author mean the local Aids initiatives which are non-profit organizations dedicated to promoting HIV/AIDS awareness in Mozambique by scaling up nation-wide prevention efforts and improving the lives of persons infected with or affected by HIV/AIDS. Kindlimuka was founded by those who were receiving counselling from AMODEFA. Kindlimuka was created around 1997 in Maputo city. AMODEFA is behind the creation of this association and that is why the members of this association use to say that *AMODEFA* is 'our father'. The first years of its existence the association used the premises of AMODEFA. By that time AMODEFA was working on programs of family planning, giving counsel to couples about issues of reproductive health. The most important part of this association is formed by nurses and other health workers. After some time, it was able to detect people with HIV problems and started to give counselling in this matter also. In 2000 the number of associations increased in Maputo due to the increasing number of infected people who, in turn, contributed to the creation GATVs (Gabinete de Aconselhamento e Testagem Voluntaria) what means Services of Counseling and Voluntary Testing such as *Thinena* and *Kuyakana kudumba*.

In addition, there are many organizations working with people living with HIV/AIDS. Examples of these are *FDC*, *Muleide*, *Kulima*, *Forum Mulher*, *AMME* and many others. These organizations work with or for PLWHA in different parts of Maputo and other provinces providing specific programmes for the Mozambican community. FDC has a specific programme *Kulhuvuka* along Maputo corridor in south region working with widows and giving financial assistance and civic education to infected people while *Muleide Kulima* and *Forum Mulher AMODEFA* are working in partnership with the international institutions and health services in care based home assistance to PLWA..In very recent years *Vidas positivas* 'Positive lives' was created. This NGO's primary aim is to providing counselling to HIV positive people. This organization tries to implement some strategies developed in South Africa. *Soul City Agency* in South Africa supports its actions. *Soul City*, is a South Africa NGO that was established in 1992 to harness the power of mass media and promote health and development in South Africa

and beyond is actually achieving its dreams. Its TV programmes or movies about HIV/AIDS are now implemented in Mozambique to help people know how to handle HIV issues.

Unlike the other provinces, PLWHA associations in Maputo have the possibility to negotiate the implementation of different programs thanks to the direct intervention government departments and other facilities. In short, the dynamic of HIV people associations in Maputo are privileged because the central services of government are based in Maputo as well as the others international institutions including the donors.

Manica province

Geographical situation

Manica province is situated in the central region of Mozambique. This region is composed by three provinces (*Sofala, Tete and Zambezia*). Manica has Zimbabwe as its neighbour.

Population

The population in this province is about 1900.000 of which a major part is concentrated in Chimoio (INE: 1997).

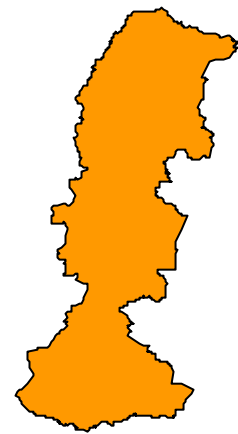


Fig.3 Map of Manica

This province was one of those most damaged by the civil war which lasted for some decades. During this war many people ran away from this province and went to other countries including Zimbabwe as refugees. During that time Zimbabwe was considered as one of the most affected countries by HIV/AIDS in Africa. It is often believed that the return of these immigrants (already infected by HIV in the neighbouring counties) to their own country after war also contributed to the increase or spread of HIV in the province or the country by large.

Besides this war, many socio-economic infrastructures in this country were also destroyed. The local government is still struggling to rebuild these infrastructures. Nevertheless, the recent political and economic crises in Zimbabwe have brought many

white framers from this country to Maputo and who have been exploring the land in this province. That is why Manica is seeing considerable improvement in terms of agriculture and trade these days. The infrastructures such as roads are also developing.

Similarly in Maputo there is in this region an important corridor created in 1990 as a way to strength the linkage between Mozambique and Zimbabwe. The corridor is from Port of Beira (Sofala) to Zimbabwe crossing Chimoio in Manica. This corridor brought large movements of people and goods from each country to another. This corridor, though economically important, has an impact on the dissemination of HIV/AIDS. The districts along this corridor (Beira, Dondo, Nhamatanda, Gondola, Chimoio, Sussundenga and Manica) are seriously affected by AIDS. The highest prevalence of HIV/AIDS in Mozambique is registered in this region with 26%, following by the south region with 19% and 9% in the north region (INE: 2004). The most apparent cause for highest level of HIV/AIDS prevalence in this province is justified by the immigration. Studies conducted by CEP⁵ also confirm that the internal mobility of people a long side this corridor has contributed seriously to the spread HIV/AIDS in Mozambique, in general, and in this region, in particular.

The HIV/AIDS Associations

Rudo kubatana is the first association that was created in this province since 1997. The province was the first one to become aware of the wide spread of this disease as it had noticed many people dying of AIDS by the end of 90s in Manica and more particularly in Chimoio. The return of displaced people from neighbouring countries was the most important reason. *Rudo Kubatana* in the first years of it existence was an important association aggregating many people with HIV/AIDS in Chimoio.

The thing that struck the most the author's mind here is the courage of people in this association in breaking silence about their HIV status (more details in chapter IV). At

⁵ CEP Centro the Estudos da Populacao (centre of population studies) belongs Eduardo Mondlane University

national level actions developed by this association became soon remarkable. Many of its activities gave this association the great reliability. Zimbabwean associations remained the role model of *Rudo Kubatana*. People learned quickly how to organise their association. They learned from what they saw happening in Zimbabwe as this country already had more experience in matters relating to HIV/AIDS as far as the 1980s.

Besides, Guinguirirai was founded in 2000 though its activities already existed since 1999. What is peculiar to Guinguirirai is the fact that emerged out of *Kubatsirane*, an ecumenical religious NGO. Among other activities *Kubatsirane* was working with PLWHA and in 2000 this organization decided to become autonomous. Thus it became autonomous even though it still remains part of *Kubatsirane*. It attends *Kubatsirane*'s meetings and gives advices on a number of issues. They still hold in common some concerns although they blocked out from each other. (Report given by Sister Rosa, coordinator of Guinguirirai, Chimoio: 2004)

GATVs in Manica started in 2001 as well as in many others provinces. In Maputo there is one support group as well as in Chimoio, Manica and Gondola districts. According to the provincial coordinator of Nucleo Provincial do Combate ao HIV/AIDS these three-support groups are preparing to form one association. The dynamic of the PLWHA in Manica complains about the financial resources to develop its activities as Manica people do not have many local donors to support their activities.

Zambezia province

Geographical situation

Zambezia province is part of the central region of the country. It has Quelimane as its capital city.

Population

Zambezia is the second biggest province and the second most populated with about three million of inhabitants (INE: 1997). Like

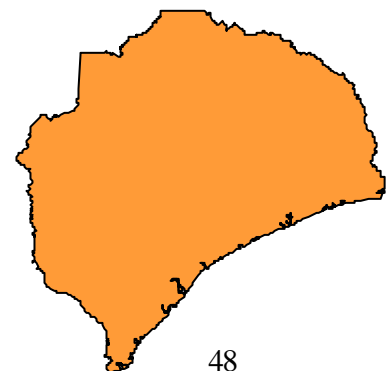


Fig. 4 Map of Zambezia

others capitals Quelimane also absorbs more than 1/3 of the provinces entire population that is estimated to be 1000 people (INE: 1997).

This province has Malawi as the country border. Like Manica province, Zambezia during the civil war saw many people migrating to Malawi as refugees. According to the data, the most refugee people of Mozambique during this war were based in Malawi (PNUD, 1996).

The linkage between Southern and Northern Mozambique is through the Zambezi River. To cross the country through this river is not easy due to the bad state that the bridges and roads in that part of the country. As result, many drivers prefer to make the turn around the river thus taking the route of north region via Malawi. Travelling by air is the fastest means of transport, but it is obvious that this is not given to the ordinary people without enough money. Despite the fact that the government is making efforts to rebuild the bridge, it is a fact that the Zambezia province remains is isolated from rest of the country. Maybe this isolation has for the time being preserved this province from high risk of conducting HIV/AIDS.

The HIV/AIDS associations

PLWHA associations in Zambezia like in Manica are not strong. PLWHA in Quelimane city has two branches: *Associacao Esperanca*, association Hope, and *Kewa*. *Associacao Esperanca* was created in 1997 and *kewa* in 2001. *Associacao Esperanca* has its origins in the provincial hospital. It is reported that this association started as result of blood tests. The increasing number of HIV people in Mozambique pushed the Blood services in this particular hospital to check all the donors of blood. Those found with HIV+ results were advised by nurses to share their burden together. From this mutual encouragement came the idea of starting an association. In 2000 other members of *Associacao Esperanca* decided to create a new branch, *Kewa*. This association is represented by a woman. *Kewa* is dynamic. It tries to extend its activities to other districts or provinces such as Mocuba, *Pebane* and *Maganja da Costa*. In terms of financial support, the PLWHA here get some support from the international NGO such as Action Aid, Save the Children and UNICEF.

“Empowerment” is the most important term to remember from PLWHA. It differs from traditional patriarchal benefactor strategies. PLWHA does not attempt to treat the HIV people as subjects; it emphasizes their participation and maintains the interaction between them, which we encourage here.

Conclusion

To conclude this chapter, the author first remarks that this study of social factors has reinforced our understanding of HIV/AIDS in these three provinces. We need, to remind ourselves that the organizations of PLWHAs need to shift their approach towards HIV. These organizations also have to approach the matter of this pandemic in different perspective. More efforts still need to be put in.

From this brief presentation of HIV overview of these three provinces, the author observed that there are several socio cultural factors that can influence drastically the dynamics of HIV/AIDS association. However two important aspects could be considered. For instance Maputo, the capital, presents more organizations working in HIV/AIDS, as well as, associations of people living with HIV/AIDS, while in Manica the active organizations could be explained by the fact of this province being close to Zimbabwe and learns from this country’s positive experience in this matter.

As a new phenomenon, HIV is a social event. At the same time, it demonstrates many unique features. This means that its impact on community life may be very different from one place to another. This section has shown that HIV/AIDS associations are capable of creating communities that not only facilitate connections between people but also provide supports for their members. Thus, the associations of PLWHA have not only the potential to promote and fight the disease among people in real life but also the capability to construct a virtual community that is part of the real life. The point is, the relationship among people with HIV through PLWHA associations becomes more and more significant. This means the possibility that PLWHA will eventually replace all other forms of associations not composed with people with the virus in the future is evident. This is proven by its new approach which is not only social-oriented but also problem-solving.

The associations of PLWA is formed essentially by poor people has led some to characterize it as a disease of poverty. However, evidence suggests that in some countries the wealthy are also especially susceptible to infection. But in general, it is likely that the poorest sectors of the population are still the most severely affected.

CHAPTER 5 - FINDINGS

This chapter begins with a brief description of the issue of stigma. It gives an overview of HIV/AIDS support groups and how these developed into associations. The comments offered by PLWHA in the support groups and associations are the most important part of this section. The chapter discusses, moreover, questions related to the internal organization of the associations. Also included is a discussion and interpretation of cultural issues obtained from the analysis of People living with this virus. The chapter concludes with a review of the funding in the fight against HIV/AIDS.

Stigma

AIDS-related stigma (or, more simply, *AIDS stigma*) refers to prejudice, discounting, discrediting, and discrimination directed at people perceived to have AIDS or HIV, and the individuals, groups, and communities with which they are associated.

AIDS stigma is expressed around the world in a variety of ways, including:

- ostracism, rejection, and avoidance of people with AIDS (PLWAs)
- discrimination against PLWAs
- compulsory HIV testing without prior consent or protection of confidentiality
- violence against persons who are perceived to have AIDS or to be infected with HIV
- quarantine of persons with HIV.

AIDS stigma is effectively universal, but its form varies from one country to another, and the specific groups targeted for AIDS stigma vary considerably.

Whatever its form, AIDS stigma inflicts suffering on people and interferes with attempts to fight the AIDS epidemic.

Here is a testimony of a man who was diagnosed as HIV positive in Chimoio, 2004:

I never told any body about my situation because I was afraid to be marginalized by them, even my wife I couldn't tell. I only spoke about my condition in the association because I knew that all were suffering from the same problem.

Another testimony quite different from the first one reads as follows:

When the doctor told me that the reason of my long disease was due to AIDS... I informed my husband. Since then, I was no longer at ease at in my house as result my husband decided to take me back to my parents where I am now. My sin was that I revealed the secret...
(Interview with a HIV/AIDS woman in Maputo, 2004).

As one can see, the issue of stigma appears in this second interview. Before, we comment more on the interviews; let us first understand what stigma is all about. Stigma is compounded by fear of an incurable disease, fear of death after long suffering, association of HIV/AIDS with sexuality, and a misunderstanding of its causes. Stigma is indeed deadly because it hinders both prevention of HIV/Aids and provision of quality care. It is also deadly because every human is a social being and when rejected, people become very affected causing death long before the virus could kill. Most of our African countries make the stigma a worse epidemic than AIDS itself (CEA/UEM: 2000).

It is now clear that those who accept their status could live for years, but those who cannot stand the stigma must die earlier than they should. This is very unfortunate because stigma is socially constructed, hence it is curable. An effective way of dealing with stigma is simply assuring people that they are better off knowing their status, that they need not give up if infected, and that there can be quality life after HIV. This is what PLWHA associations are trying to achieve.

These extracts of the interviews demonstrate the level of discriminations related to the HIV positive people, on the one hand, and the importance role played by PLWHA associations where people can talk to one another about their sero status and share experiences.

Origins and motivation for creation of HIV/AIDS groups & associations

The difference between support groups and associations is that the support group is an informal group while the association is a formal group recognized legally by the ministry of justice on one hand, and the existence of structure elected by the assembly on the other. But the objectives, characteristics of the members, the activities are the same.

Some times people of the certain support groups are also members of the associations. It is worth signalling here that most support groups are attached to the hospitals which are their spheres of operation.

The support group origins and function

The establishment of more GATV⁶'s services of HIV-AIDS voluntary counselling and testing help people to check their sero status. These services were created by the CNCS in coordination with the Ministry of Health. The aim of these services to ensure that any one who wants to know about his/her situation does it without any monetary costs. The services are intended to be countrywide provided in order to prevent the spread of HIV through sexual intercourse, maternal-child transmission as well as by blood transfusion. Given this context, the services attempt to reduce the morbidity of HIV- infection through early or prophylactic treatment of HIV infected individual what should include antiretroviral therapy.

According to CNCS, the above services will be provided step by step through the country. They are first guaranteed in the cities where people are the most concentrated. The same source contends that around 2010 these services will cover all health services (CNCS: 2004).

⁶ GATV Is an acronym meaning Gabinete de Aconselhamento e Testagem Voluntaria (Services of Counseling and Voluntary Testing)

Another important aspect related to these services is that wherever they are, they are backed up by **support groups** in order to give an emotional comfort to those people tested positively. As already explained, the integration of people in these support groups is done by GATV services. As soon as people have tested HIV/AIDS positive, they are immediately encouraged to become members of one of these support groups.

There are activists working in these groups whose job is to sensitize people to join the group.

One of the Maputo HIV positive activists went public on her own HIV status and had this to say:

I'm an HIV positive working in this GATV as an activist of this hospital. This job is important because people who receive positive results, if they don't get support of some sort they can even commit suicide. So we stand here as people went through the same experience but alive... and therefore can help others (Interview with an HIV positive activist, Maputo: 2004).

Ivone, coordinator of one of the support group also acknowledges the good results of her work:

I work here as a coordinator of this support group. I used to work for another organization sensitizing people door to door in the community. But when I realised that MSF Luxemburg wants some one for this kind of job, I applied and was accepted. I'm happy doing this because it is a great joy to see that the person who was knocked down by the disease stands up and walks after counselling. It is then that I realised that I am doing a useful job (Ivone, Maputo: 2004).

The drastic growing number of infection in the country and the presence of the support groups can help people to become more and more open and seek for hospitals where they can confirm their status.

It is in this context that Maputo support groups such as Thinhena, Kudunba, Kuyakane and Thinhena youth were found useful to HIV-people. In Manica province there are support groups in Chimoio 'hospital dia', in Manica and Gondola. In Zambezia - Quelimane there is also a support group operating in the 'hospital dia'. Considering the experiences of the already existing associations created from these support groups, it could be assumed that more HIV-associations will emerge in Mozambique. Some of these support groups have contracts with institutions such as Medicos Sem Fronteiras Luxemburg and Switzerland.

One thing that is clear is that none of these messages have led to behavior change. Many of those who were interviewed belong to these support groups and say that they feel secure and happy as members of these groups because they have the opportunity to talk, to share the same situation with others. A woman from Thenema support group confirmed this feeling saying:

When I knew that I'm HIV positive I thought I'm going to die...I really lost the interest in life... but now in this group, I learnt that I'm not alone and I can live longer if I take care of myself (Member of Thinhena, Maputo:2004).

These groups are important because, after a person receives a positive result of HIV feels emotionally down. As a young girl pointed out:

*When I knew about my results, I felt abandoned and already dead".
(Member of Kindlimuka, Maputo: 2004).*

To elucidate how these support groups operate the author single out *Thinhena*, the group that the author worked intensively with. The author attended many of its meetings and conducted interviews with many of its members. This group was formed in 2000 as a result of the establishment of GATV in health centre of *1 de Maio* in *Polana Canico*. The group is supported by *Medicos Sem Fronteira* Luxemburg.

In *Thinhena* there are more than 90 members that meet regularly weekly following the established calendar:

Monday is the day of general meeting (i.e. for all members of the associations) where they deal with general issues related to their status and the stigmatisation they are victim of in their work places and how to handle that.

Tuesday is the women-meeting day. On this day it is only women of the support group that are allowed to attend this meeting. Ivone Joaquim coordinator of this group says that she understood that women in the general meetings didn't speak comfortably about their problems. This attitude is caused by gender- power relationships already emphasised on. Women are afraid to expose their ideas and tell their experiences because they can suffer some reprisal from their husband at home.

Wednesday is the day of youth meetings. These meeting involve both boys and girls. Specific problems related to their age are discussed. The major concern of this group is to create awareness of how they have to deal with their future despite their status. Issues around marriage and education are also discussed.

On Friday pregnant women attend the (PTV⁷) *Programa de Transmissao Vertical* 'Vertical Transmission Program'. This program of prevent mother-to-child transmission of HIV is supported by USAID in conjunction with the Ministry of Health and others partners. This started in 2002 most in urban areas making a volunteer counselling and testing available for pregnant women as part of antenatal care including greater use of safe delivery services, family planning to reduce mother-to-child transmission, and anti retroviral therapy (Nevirapine) for these positive pregnant women (USAID country profile: HIV/AIDS). Beside all these aspects is also including counselling on appropriate infant feeding.

As women are taught not to breastfeed their little ones and knowing that the level of income for most families in Mozambique is a problem, it was found that such meetings

⁷ An acronym in Portuguese meaning Programa de transmissao vertical what means in English program of vertical transmission. This program is about pregnant women attending the treatment as a way to avoid the transmission of the HIV to the baby.

be done in conjunction with some NGOs such as Santo Egidio and World Food Program in Maputo and Quelimane that supply milk to these babies till six-eighteen months though these programs do not still solve this problem given the fact that babies need milk up to two years. The question is often what will come after six months?

Vigorous controversy exist about whether HIV infected women in developing countries should choose the formula of breastfeeding their infants or not. Breast milk, as we all know, especially in the first months, are vital for the survival of the child because it contains nutrients and antibodies which are needed for the development of the immune system of the baby but have inherent risk of transmitting HIV to the baby. Not breastfeeding babies eliminates HIV transmission but incurs risk of increased mortality whereas breastfeeding has multiple benefits but entails risk of HIV transmission it is estimated by UNICEF that million non –HIV related death per year can be prevented globally through breastfeeding (Coutsoudis, 2002:15).

The other problem is that when infected women are asked why they don't breast feed their babies they have difficulty to explain the reason. Confidentiality is also at risk. Pressure from family especially mothers - in -law force young women to breastfeed thus, increasing the risk to their children to be infected.

From the support groups to the associations

According to the interviews support groups decided to become associations because they felt the necessity to act outside of the hospital and be recognized as groups which have the capacity to talk about situations on behalf of people living with HIV. They started to be organized in way to act outside the hospital, integrating both infected and affected people suffering from the same problem. They were encouraged to establish their own associations.

Then some members start to follow the necessary path to create a formal group with their own vision and specifics aims. Are examples Thinhena and Kubumba in Maputo.

«..we thought to create our own association to explain our situation to whom it concern...and we wanted to be recognized as a organized group

of one's own free will to fight against HIV/AIDS breaking the silence(...) another problem is that the donor institutions only give support to organized groups and recognized by the government...». (Elias president of Thinena , Maputo:2004).

This is confirmed by Elias in Thinena association who says:

We thought to create our own association to explain our situation to whom it concern...and we wanted to be recognized as a organized group with our own free will to fight against HIV/AIDS, breaking the silence(...) Another problem is that the donors (institutions) supported only formal organized groups recognized by the government. (Late Elias president of Thinena association, Maputo: 2004).

Rensida, a national network of PLWHA has been useful by supporting some groups preparing their documentation to become associations. This national network has been supporting also in writing projects and finding donors to support these associations. The most important role of this national network is to co-ordinate the activities of its members, on one hand, and to represent interests of its members in the government and others institutions. It is in this spirit that associations such as Thinena and Kubumba in Maputo were formed.

Overview on the associations

In Mozambique two phases can be distinguished in the creation of HIV associations. However, our purpose is to highlight them and the different metamorphosis they took overtime. The first category could be sent back to 1997-9 when timidly people of HIV/AIDS formed the first associations. In this time these associations were hidden and only people directly related to them knew about their existence. Some NGOs and others institutions were behind the creation of them stimulating PLWHA associations to work with. Later on, these people decided to organize themselves into their own associations. Examples can be given of *Kindlimuka* in Maputo in 1996 and Kubatana in Chimoio in 1998. This word '*Kindlimuka*' means in Tsonga 'wake up'. In other words, it is an invitation to take action as time has gone.

This command fits very well in the context of HIV/AIDS matters where people need to wake up and fight against HIV. Kindlimuka, the first group of its kind in the country, was founded in 1996 and officially recognized in 1998. Today it has more than 330 members, of whom the great majority is HIV-positive. The association strives to reduce the stigmatization of people living with HIV/AIDS by breaking the silence and speaking openly of the illness. It encourages other groups of PLHWAs to seek official status for their associations with the aim of establishing at least one association for each province in the country.

Rudo Kubatana in Manica province is the other association belonging to this phase *Rudo Kubatana* in *Shona* language these words are expressed to encourage HIV positive people to stay together in love ‘people has to be together and in love with each other’⁸.

Associacao Esperanca in Quelimane-Zambezia also means in Portuguese language ‘Hope Association’. This is a challenge to HIV- positive people to think positively and be full of hope for future despite their condition.

The objective of these associations was to give the membership courage and hope. The native names given to theses associations attract local people who deeply understand the meaning behind these names. However, the idea that PLWHA associations can help HIV-positive people is not new, nor is it exclusively African. It does exist in other places as well but seems to be a successful approach in the Mozambican context. The success rests on the fact that most HIV-people feel free to share their burden with their peers who suffer from the same disease.

The second generation of associations of PLWA can be considerate since 2000 until nowadays, in this period observed a “boom” of these associations, the reasons behind this increasing of associations could be associated to the awareness of the government with

⁸ This explanation was given by the president of Kubatana association in Chimoio during the interview in 2004

this pandemic that culminated with the creation of the CNCS⁹ in 2000 a governmental institution with the task to coordinate all actions related to HIV/AIDS countrywide. This measurement shows that the government was committed now more seriously. The HIV/AIDS was assumed as an emergence national matter so including in the priorities of its agenda. (Plano Estrategico Nacional: 2004)

PLWHA as a tool to Breaking the Silence on HIV/AIDS Epidemic in Mozambique

As the fight against HIV/AIDS intensifies in Mozambique, more and more people living with the virus are volunteering to share experiences but we should admit that this is still happening in the confines of these associations or support groups mentioned above.

Janzen in the quest for therapy in lower Zaire found that the people with the same problems, are more confident and the communication becomes more simply when they share the same culture .(Janzen: 1978).

As long as people are ready to talk about it, HIV/AIDS has spread at a fast rate in this country. People living with HIV/AIDS in the associations share their experiences with one another. This indicates that people start now to accept the reality of HIV/AIDS and respond with full understanding of the complexity of the epidemic and the socio-economic challenges it is posing to the nation.

These associations are the best way to deal with HIV as many people make their HIV status known there. The associations also present talks to various groups, help organize HIV/AIDS awareness and education campaigns, and provide HIV/AIDS pre-test and post-test counseling and psychological support to those infected and affected. It is believed by many that people living with HIV/AIDS are potentially the most effective educators, counselors, campaigners and care givers given opportunity and support.

⁹ CNCS Conselho Nacional de Combate ao Sida is an acronym in Portuguese meaning: National Council of Fighting AIDS.

People living the virus are starting now to make HIV/AIDS visible through personal testimony, using sensitive training, prevention campaigns and workplace counseling to bring AIDS into the open and encourage an effective and humane response by governments and civil society.

But their meetings remain the first place where the silence is broken because they are open in speaking about their problems. Those who have lived with disease long enough share their experiences with the new members to encourage them. A senior woman of Thinhena support group declares this, for example:

Times ago people in my district used to point fingers to me saying that she has AIDS. I was ashamed about, but now when I hear some one point to me in that way I confirm my status and I advice him/her to go testing because he can be also in the same situation like me....(Amelia, Maputo:2004).

The whole idea is to give a human face and voice to the epidemic in the minds of people not directly touched by it, "We want to facilitate the acceptance of the presence of HIV/AIDS in the community" (Onen, 1999:2). The more we start talking about the epidemic, the more people will accept it as a reality and refrain from behavior that would put them at risk.

Those in positions of power should strengthen the capacity of communities to discuss the epidemic and the changes they must introduce to survive, and increase effectiveness of national HIV/AIDS policy development programs as the community-based organizations (PLWHA) have started to show the example with its counseling and care activities programs.

Intellectuals should also contribute their knowledge and experience to decision making processes to ensure effective national response to the epidemic. We need to know that we are all at equal risk contracting the virus. Above all the government must make information and tools for prevention and support available to all citizens, increase investment in programs for young people, promote the development and implementation

of policies and legislation that will ensure the epidemic attains priority in the government's budget.

Characteristics of the members the Association

I attempted to gather full data on the characteristics of these members including sex, age, level of education and employment. However, because of different reasons such as the lack of update data base of associations, it was not possible to find these aspects in all associations. Except in two associations *Kindlimuka* and *Associacao Esperanca*, it was possible. The presentation of this data is an attempt to give a picture of what these associations are like. This data is reliable because it is full of inconsistencies.

Characteristics of the associations

Organizations.	Location	T. number	male	female	employment	education
Kindlimuka	Maputo	330	124	206	85 ¹⁰	¹¹
Kubatana	Manica	138	66	72	65 ¹²	
Shinguirirai	Manica	100	40	60	25 ¹³	
Associacao E	Zambezia	350	150	200	22 ¹⁴	50% ¹⁵
S g. kudumba	Maputo	About 50 ¹⁶	32	18		
Thinhenha	Maputo	80	30	50	80% - 15% ¹⁷	

Table 2 characteristics of members of the associations

¹⁰ This number of people employed in this association seems to be high because it includes activists

¹¹ Information about education is not possible to be presented in the table because the data are estimated. For example, the number related to high education is referring to honorary members, while, 35% of the members in these associations never been in the school

¹² Most of them as activist employed through the association

¹³ All employed as activists

¹⁴ 17 of this number are working as activists 8 outside of the associations

¹⁵ 50% are illiterate while the other 50% attended primary school and a few % secondary school

¹⁶ Means that was not possible to get the precise information due to the fact that some member no more attend the meetings of the group

¹⁷ This association estimated the data in % where 80% are unemployed and only 15% employed

Associations must be managed and run primarily by People Living with HIV/AIDS, both affected and infected but mostly the infected ones. They must have or establish a board and officers, as well as an elected finance sub-committee, and a medical advisory team. They must also keep minutes of board meetings and up to date financial records. Associations must demonstrate that they do not discriminate on the basis of gender, religion, ethnicity, sexual preference, and social class; or against sex workers and drug users. The selected members should have demonstrated commitment to their own health by their past and present behavior, such as participation in the association's Positive Living programs.

In short these groups can be represented as this:

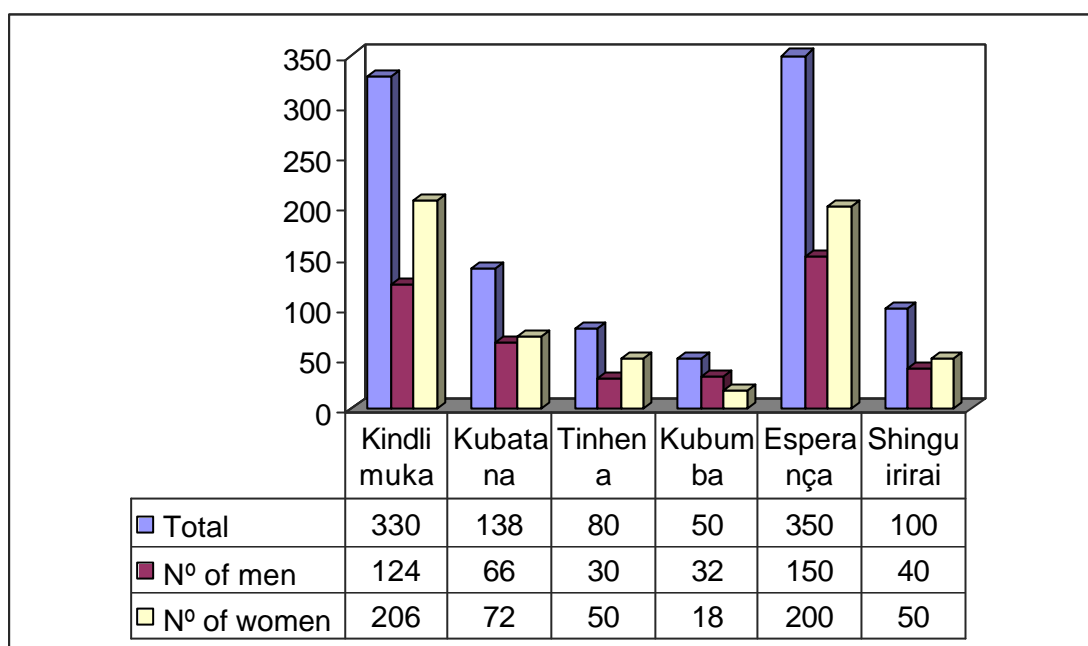


Figure 5. Distribution of Males and Females in the Associations

Gender Issues in the associations

Following the above tables, it is clear that the number of women in all associations is higher than that of men. This is because women find themselves in situations where they need to be tested than men do. They get tested when they are pregnant, they are advised to have an HIV-test and if they are found positive, they are integrated in the associations. Patton confirms this when she says that “many times these women are surprised confront with this situation in conjunction with undergoing some other forms of health care mostly related to their reproductive health” (Patton, 1994:128).

But beside these reasons the number of women increases in the associations because some of them are taken by their sero positive husband advised in the hospital to check their wives' status. By contrast, women do not have enough power to bring their husbands to the associations. An HIV-positive woman confirmed that when she knew about her situation, the hospital advised her to take her husband for testing. The husband in return responded angrily saying:

get out from my home, I don't want to hear this in my place if you have got AIDS it is your problem don't include me in your affair

As already emphasised in chapter 2, the relationship between women and men in Africa are characterised by asymmetrical power relations, which constitute real barriers to women's social development. Women are always silenced by men in many aspects, especially when it comes to sexual matters.

In fact, if we accept that the most important means to transmit HIV/AIDS is by heterosexual where both men and women can be affected the gender relations are indispensable to be considered. In African society the "women often have too little power within their relationships to insist on condom use, and they have too little power outside of these relationships to abandon partnerships that put them at risk" (Baylies, 2000:6).

Even as Baylie and Bujra think that the best thing to do would be for women to challenge men's power and negotiate for safe sex (Baylies&Bujra, Xii: 2000). But this challenge is not an easy task considering the process of socialization in Africa including cultural practices such as polygamy and rites of passage (initiation rites) that put women more and more in subordination conditions. In these practices women are taught to surrender before the male power if they have to be good house wives.

In almost all African cultures, "women's worth is equated with their child bearing and proofs the men's masculinity (Patton, 1994:140).

To confirm and reinforce this argument it could be important to state the following quote from one of my interviewees:

I'm 29 old and have got three children. The oldest is of my first marriage. He is 14 and another is 9 and the last is this baby here. These two last are of my second marriage. My husband died five years ago. I was always sick and had a skin disease (herpes) and TB as was diagnosed at hospital. I was convinced that I will soon die because I had the same symptoms which my husband had.

Given the persistent of my illness I had to consult the doctor and he advised me to take a HIV test. I did and the results were positive. Finally I was told that I'm HIV positive. At the hospital I was advised by an activist of Kubatana to join his association. So, after the first visit, I decided to be a member of this association. The first day when I get there I recognized many people there because some of them used to come at my home with my late husband as his colleagues. So I realised that every day when he said that he is going to work, he was actually coming to the association. I remember that he never told me where he was working and what kind of job he was doing. My husband was HIV/AIDS positive and he knew it, but never told me about his status. The life at home was natural until he died. Now I have another partner and I got this baby but last year my baby died. We are together in this association....

When asked if she knows that it is not good to have babies because they can die as result of this sickness, she replied:

I know, at hospital they teach us about these things. They say that it is not good for an HIV positive to be pregnant because the body will get weaker and weaker and eventually die. But what will I do? I'm still young and my husband says that he can only pay lobola (bride price) at least if I have a child with him.

In my family no one knows about my situation. It is not easy to tell people about this disease here in Chimoio because you can be discriminated by all people including the family members. Now I'm working here at the association as a cleaner as a way to have some money to support my children.

We speak of African women as being sexually subordinated by men. That topic is also debatable because on the biological point of view, women still have an important role in African society. A proverb from Ghana declares that: A woman is a flower in a

garden; her husband is the fence around it'." (1). That is a beautiful picture of women in African society. The main idea here is to link human life directly with God through the woman. She is created by God, and in turn becomes the instrument of human life. She rightly becomes the one who passes on life. With such a belief, African people both men and women see the bearing of a child is very important than the fear of having one's child infected by HIV/AIDS.

Level of education

The second aspect that comes out from these associations is the level of illiteracy. A country in which 70% of the population resides in poverty and illiteracy the disease (HIV/AIDS) can only be expected to be rampant. This is so because the community has no exposure to programs that can help them and inform them to fight this pandemic and therefore the risk of vulnerability of infection will continue unless alternative measures such as the ones by PLWHA are effectively adopted in the entire country.

There are many reasons for AIDS education. The first of which is to prevent new infections from taking place. People should be given information about HIV, how it can be transmitted, and how people to protect themselves from infection. A second reason that AIDS education is needed is to improve quality of life for HIV positive people HIV+ people should be taught about the importance of not passing on the virus. The third reason people need AIDS education is to reduce stigma and discrimination. In many countries there is a great deal of fear and stigmatization of people who are HIV positive.

This fear is too often accompanied by ignorance, resentment and ultimately, anger. Sometimes the results of prejudice and fear can be extreme, with HIV positive people being burned to death in India. Discrimination against positive people can help the AIDS epidemic to spread - if people are fearful of being tested for HIV, and then they are more likely to pass the infection to someone else without knowing (HIV&AIDS Education, 2005)

It is a fact that the people who are most urgently in need of HIV education and in these associations are poor or ordinary people. Those educated people who hold high positions in the government or local authorities though HIV+ are completely absent in these

associations. They get their assistance or treatment from private clinics or outside the country. This is so because of the fear of discrimination in Mozambique.

Unlike these educated people, the uneducated ones feel free to talk about their sero-status. They appear on TV programs confessing publicly being their sero status. TVM program “Vidas positivas” makes efforts to bring middle class people to do the same but they timidly respond to this program’s invitation. Maybe the reason why the poor people easily break the silence is because they have not much to lose and in so doing they know they will maybe get some money or others forms of compensation to face the starvation problem.

This was confirmed by two young boys in Chimoio who told that when they broke the silence by declaring their HIV status they used to receive some incentives.

“... when we gave this kind of information about our HIV status we used to ask for some incentive... and coming out in the open is not easy... many organizations used to give us some money...” young boy from Guinguirirai Association, Chimoio: 20004).

From a handful of courageous individuals who went public about their HIV status in 1999 in the capital, Maputo, there is now a nationwide network of 28 associations of people living with HIV and AIDS (PLWAs) (Rensida: 2004). Yet stigma and discrimination persist.

Considering the level of education and employment, one can conclude that these associations are weak. On one hand, it is not easy to do voluntary work and the same time try to feed the family since the majority are unemployed and on the other hand, because the members are illiterate, they can not make well-informed decisions in the running of the associations.

The general picture of Mozambique is that is a poor country ravaged by AIDS with a high unemployment and low education level. Despite this picture, there are some rich people in good positions in the government and civil society. Although these may suffer from AIDS, usually they do not belong any of these associations.

This kind of attitude is not good when you want to break the silence. Mozambique is still not doing well in breaking down the culture of silence among influential people. The experience of Uganda shows that when influential people come out in the open and announced their HIV/AIDS status, more people were influenced to do the same. It also led to an increase in sensitization of the general public on issues that relate to HIV/AIDS.

Organizations like TASO and individuals like Pilly Lutaya in Uganda “ put a human face to HIV/AIDS” . Ordinary people were able to associate AIDS with rich people, and joined hands together in fight against HIV/AIDS. (<http://www.aidsuganda.org/pdf/role-ofvct.pdf>).

Unlike Mozambique in many countries such as South Africa we hear stories from people who live or have in some way been affected by HIV/AIDS. They reveal their status honorably. However, for the vast majority of people living in these counties, human rights are respected and people have learned to live with HIV+ people with dignity. This is a good example to follow for Mozambique where everyone needs to learn how and why not to discriminate against positive people.

Altman comparison of HIV organizations in Africa with those in USA found that in the USA these organizations are far stronger and organized in terms of political representation and advocacy than they are in Africa or other developing countries (Altman: 1994: 58-59). In our understanding what makes them this way can be attributed to wealth, fight against discrimination and high level of education of those working in these organizations.

Employment and HIV care

HIV-People in Mozambique, estimated at 13% of the total population within a country continue to face difficult lives without access to any basic services.

Education, Transport, Health and Employment services do not exist or are very scarce and do not satisfy the needs of this social group. The mass media do not give attention to the specific needs of people.

Mozambican society in general, continues to look at people with disability including HIV- people as useless and incapable; subjects them to constant marginalization and discrimination; and gives them no space to participate in the massive effort of recovery and development of the country.

It is important to observe (see tables 1-7) that most members of the associations are unemployed. In this item we used two categories of employed people: one referring the people employed outside the association in public, private or informal sector, and the other referring to people considered employed by the associations working as activists in the GATVs or hospitals. Since they receive their minimal incentive, they consider themselves as employed people.

This incentive correspond about 500000\$00mts equivalents about R 150\$00 per month. This amount is insignificant if it has to cover the needs of a household with at least 5 to 6 people. In INE and PNUD report, Mozambique is considered as one of the poorest countries in the world where people are living with less than one UDS dollar per day. The actual minimum salary in Mozambique is 1.200.000mts meanwhile the basic needed for a household of 5 people are calculated in double of minimum salary in 3.300.000mts (OTM Cental Sindicato: 2003)

Given the low possibilities of employment most people in these associations are concerned in having this kind of job as an activist and they consider themselves as employed despite this low income.

For example in Maputo the coordinator of the Kudumba support group, said that when the association was formed most of members got employed as cleaners or gardeners at the hospital where the association is based. That attracted other people to join the group so that they could benefit from the incentives. It, was not possible to employ all or the people because the jobs were limited (coordinator of Kudumba, Maputo: 2004).

It is in this regard that the board of the association came to the understanding of the fact that people working in the association with children to look after qualify (should obtain)

for such support grant for survival. The president of association Kewa in Quelimane argues:

One of the most important objective of the association is to ensure that the members have the minimal for survive... many of us are not working because we lost the job due to the illness... so we have to do something for them in that way (Ana of kewa association, Quelimane:2004).

In this way, we see the PLWHA as having gone one step further from their emphasis on HIV/AIDS education to care. Education was (is) important, but now that the pandemic is full-blown, the need for care had become more urgent.

In South Africa a disability grant of R740 per month (US \$108) is available to people with CD4 cell counts below 200. It is believed that HIV-people who cannot work find themselves in the category of those with disability and are eligible to such grant.

Unfortunately, there are some misconceptions among the young girls who sleep around with men without condom. They do not mind contracting HIV so that she could access the disability grant. Here also the South African government (the department of social development) has the duty determine how to improve the grant system and prevent such perverse incentives.

Caregivers need to receive a salary, which can help them and their families to survive. We do, however, agree with the fact these people have been trained in basic nursing skills, but are not health educators or full nurses as such. But it is also true that they cannot work for nothing.

In short, a number of issues impinge on the PLWHA's contribution to HIV/AIDS. High illiteracy rates, unemployment, underemployment, lack of scientific awareness of HIV/AIDS epidemic, a high population growth rate and cultural misconceptions, are some of such issues affecting the policy that PLWHA proposes to address.

Description of the association's offices

This section describes PLWHA addressing HIV/AIDS in Mozambique that were visited during my research in Maputo and other provinces. The offices outlook, the associations' functions and chart will be presented as well.

To start with, most of the offices of the associations are small houses in annex of the main house (dependencia) and in degradation situation (i.e. without renewal painting, electricity and water) with the exception of kindlimuka in Maputo and kubatana in Chimoio whose offices are independent properties.



Figure 6 This is the office of *Kindlimuka* association with the logotype in the main entrance

But both of them faced some problems related to the payment of the rents. Kindlimuka , for example, moved twice from one office to another in 2004. Kubatana was in search of a less expensive and affordable office as their donor notified them that he will stop paying the rent simply because the association mission in the province was nearly to finish.

Others associations work together with NGOs or other institutions as they are unable to afford the rent. This is the case of Guinguirirai in Chimoio working at Kubatsirane office. Kuyakana in Maputo is also working in the premises of the Rensida office while

Associacao Esperanca is with MONASO in Quelimane. And finally Kewa in Quelimane is given a small room in the provincial hospital.

It is also important to emphasise on the fact that these offices are located in hidden places. Is not easy to find them unless one is taken by hand to these places as they do not even have the advertise signals pointing to where they are located.



Figure 7 the road to get the *Thinhena* association some where in the district of Laulane close to Maputo city



Figure 8 The *Thinhena*'s office association

Mozambique faces many challenges. Even though PLWHA continues to play a paramount role in educating people about HIV/AIDS and sharing of experiences with the government, the political parties about this pandemic.

Structure and function of these associations

The way in which HIV people associations are structured is based on the one adopted by the most of NGOs in Mozambique. To be legally recognized an association in Mozambique an organization has to be recognized by the ministry of justice. Ten members at least have to sign the status in representation of the others members. Others requirements are: the *estatutos*, describing the aims of the associations, general presentation about the members, the structure of function of the different organs.

The basic organization chart looks like this:

The structure of the organisation: Principal organs and the function

Organization Chart

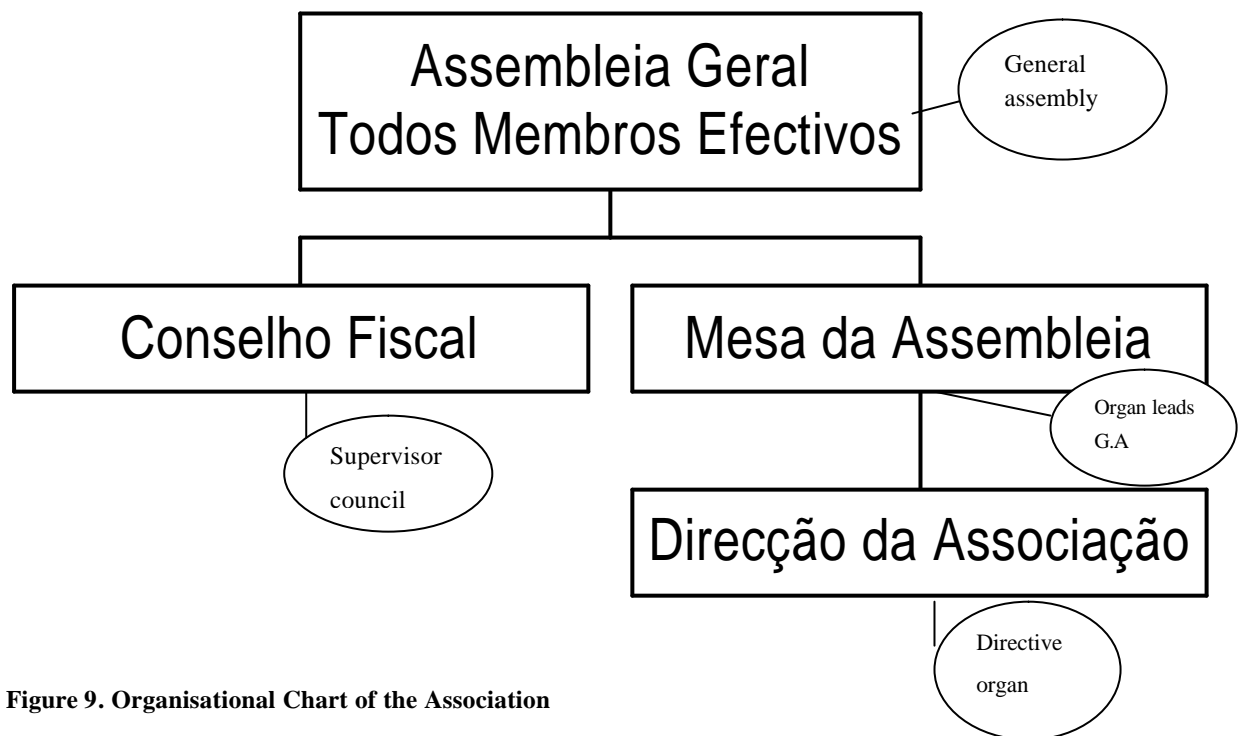


Figure 9. Organisational Chart of the Association

Sources: This organization chat was based on different status of the association (Thinhená, kindlimuka, Muleide, AMMe, kubatana).

Function of the associations

According to this chart the principal organ is the **General Assembly**, a president supported by one vice president and one secretary composes the presidium of this assembly. This is the main organ because it is where all aspects regarding the life of the association are being discussed. The alterations of the status, admission of new members, examination and approval of annual activities reports as well as financial reports are also part of this organ's agenda. The ordinary meetings occur once a year while the extraordinary can occur anytime when required by the direction or by 1/3 of its members.

Below the general assembly comes a **Directive Organ**. This one is composed by a president, one or two vice presidents and the executive secretary. This organ is the executive structure that deals with the daily activities of the association. The directive organ represents also the interests of the members. It is, in addition, responsible of the mission and vision of the association in the country and outside.

The **Executive Secretary** is not elected in the general assembly; he/she has to apply for this position according to the requirements set up by the association. The secretary spends her/his days coordinating meetings, making travel arrangements, and managing schedules. In between, she answers telephones, emails, and faxes. His/her major function of the Executive Secretary is the coordination of activities from the association's members, donors, and the international organizations.

The other important organ is the **Supervisor Council**. It is also composed by three members who are: the president of the council and two vocals members. This is also an important organ because it supervises all the activities of the association.

Normally these organs have the duration of three/ four years. Candidates of different organs have to observe three conditions: (a) to be effective members, (b) to be a HIV+ and (c) have leadership qualities.

As far as the schedule of other organs is concerned, their members have specific meetings weekly. They also have sometimes meetings with the directive members to analyse different activities.

As regards **the membership** of the association, we distinguish three general types, which are:

- The effective members,
- The honorable members and
- Sympathetic members.

The effective members are all HIV+ people who identify agree with the aims and objectives of the association. They are the key members not only in terms of numbers but mostly because they are the real cause of the existence of the association. Most of them are recruited through the activists working at the GATVs services. These activists start by presenting their associations and explaining the advantages of being member based on their own experience. It is in this way that they have been able to convince and attract as many people as possible. The process of becoming a member usually follows the same pattern. One member explains this process as follows:

[...] In 1999 continuously suffered from malaria and headache. I was also losing weight considerably. The medicine I was taking didn't solve the problem, so the doctor advised me to take a HIV test... the result was positive. Before the test I was asked by an activist of Kindlimuka to be a member of this association, and I joined.

Another member in Manica explained how he became a member of Guiguirirai in this way:

I took an HIV/AIDS test because I was always sick. I was told by some activist of this association about the advantages of being in this association. So I decided to visit the association and later I became a member...

Most people become members of the association after being referred to them by activists in the hospitals and GATVs. Stories such as these are numerous. Two aspects came out: the first one is that people normally go for a HIV/AIDS test when they got a persistent disease. The other aspect is that people become members of the associations because of the job of the activists at the hospitals inviting HIV positive people to join these associations.



Figure 10. Members of Kindlimuka association in the office.

Honorable members are people with influential positions in the society. These are, for instance, the members of the government or the civil society. In the Kindlimuka association we have members such as the prime minister, the minister of health of Mozambique, and the national head of HIV programs in the health ministry. There are also members of international agencies who contribute financially for the advancement of the association.

We have finally the **sympathetic members**. This category includes people working in the field of HIV from different sectors of the society as well as people working in the health services. It also includes anyone interested in HIV matters.

Rights and obligations of members

To be involved in the activities of the association gives one the freedom of speech in issues related to the association. Any member is in the obligation of paying a symbolic amount of 1000.00mts (i.e. some cents if converted in South African rands) as a symbolic contribution to the association.

Being a member of an association is very beneficial. One of most important benefits could be to access automatically the ARV treatment but is not what is happening. The government has a policy on the provision of antiretroviral treatment (TARV) that

involves these associations. The section of the Anti-Retroviral Treatment in Mozambique (Section 4.4.3.1) below expands more on the benefits of being member of the association and the role of this treatment.

The association and the Anti-Retroviral Treatment

As part of their rights members of these associations stand the chance of benefiting an efficient HIV treatment.

In theory, there are 3 strategies to contain the HIV/AIDS epidemic:

- To vaccinate everyone against HIV;
- To change sexual behavior;
- To provide anti-retroviral therapy (Gorik Ooms, 2004).

Of these three, the two first will take time before the change occurs. The countries, who favored the prevention via change of sexual behavior such as Uganda, now start to upscale anti-retroviral treatment. Effective anti-retroviral treatment seems to be the best option today but it requires patients to know their HIV positive status in an early stage of the syndrome.

Kindlimuka and GASD were among those associations that tried to address this issue of anti retroviral treatment in their programs. But according to the rules of the country the anti retroviral treatment (TARV¹⁸) is administered following the principles below:

To be eligible for this treatment one must fulfil the following:

- The confirmation of HIV/AIDS positive test by any national service of health.
- The level of CD4¹⁹ cells must be tested below 200 (point which indicates AIDS).

¹⁸ TARV is an acronym in Portuguese meaning Tratamento Ante Retroviral translated to English could be Anti Retroviral Treatment .

- Have at least one individual around who can assist in administering this treatment.

It should be noted, however, that this treatment is provided to all those who are infected by HIV independently if is or not a member of any association. This program is in the responsibility of the Ministry of Health. The ministry has a national program for this kind of treatment. There exists a specific program that is at the disposal of the members of HIV /AIDS people that belong to the associations. In other words, this treatment does not privilege any one but every body has right to it.

According to this ministry the TARV already started in Mozambique in 2000. Each hospital receives for the TARV program at least 75 new cases per month. In all provinces the workers of this program confirmed that people are really adhering. In Chimoio, for instance, the Dia hospital receives more than 75 new cases per month because this Hospital has been receiving also patients from different districts of this province. (Interview with the director of health, Chimoio: 2004).

According to some patients the effects of this treatment are visible and the treatment is therefore seen as effective. One of the patients at Maio Hospital acknowledges:

[...] when I started this treatment, I was too slim I couldn't even work, my mum had to carry me like a baby...but now, as you can see, I'm now putting on some weights ... people don't believe that I am sick (A patient of I de Maio hospital and member of support group, Maputo:2004).

However, to be administrated such a treatment, it is important to be aware of its side effects. Therefore one needs to feed on a solid and nutritious diet. But as many people live under poverty in this country, we believe that starvation could be also the major reason for deaths. On the other hand, interrupting such a treatment does not help the patient at all, it does, instead, create the virus' resistance to the medication.

¹⁹ CD4 or (t cell) lymphocytes are a group of white blood cell that normally help guard the body against attacks by bacteria, virus and other germs. When CD4 has decrease progressively to 200 cells or below the person has developed AIDS (<http://www.intelihealth.com/IH/ihlih/ws/h www/>)

Anyway, Muleide, an activist working in some suburban area in Maputo one said that people in general are reacting well to the TARV programs. Another aspect to it is that, the experience of care home-based care services are applied in so many developing countries because the health services cannot afford to deliver their services to a huge number of infected people. As a new experience there are some difficulties in dealing with them. That is why it is accepted that HIV associations deal also with such cases though requiring a little bit of expertise that most activists do not have.

The important is that the ART is shown efficient to minimize the AIDS. People who already started this treatment have given good reports. The Mozambican government is lobbies also to have more money in order to subsidize these drugs for more HIV positive people. The actual cost of ART treatment in Mozambique is about \$ USD 250 year per person. Is too expensive for a poor country like Mozambique, that's why the CNCS National council of fighting HIV/AIDS assumes that the first strategy should be the prevention. (Plano Estrategico Nacional: 2004).

Activities & responses of members belonging to the associations

Much of the counseling, education and peer education work which is carried out with HIV positive people is conducted by HIV positive people. Many projects are shaped by HIV positive people themselves, given the insight they have into what it is like to live with HIV / AIDS. A good example of such a service - run by HIV positive people for HIV positive people - is *Kewa Association* in *Quelimane* where one of the members stresses the unity among members in the following terms:

*Here we are like brothers and sisters. We use to come here to talk each other because at home we don't have the same comfort we have here
(Member of Kewa association, Quelimane: 2004).*

The other membership expressed also his feeling in these terms:

I can't lie to you. I'm feeling much better here than at my own home. Here I got friends with whom I can joke and talk bout any thing... So, I come

every day here and spend my day joyfully (Kewa association, Quelimane: 2004).

In short, these associations in all the three provinces are developing the same activities:

- Mutual support in the association through home visits.
- Educating people at the market places, in schools, workplace by making use of themselves as examples of HIV positive people.
- Giving counselling at the services such as GATV and hospitals.

The activists of these associations receive themselves a special training from national organizations such as AMODEFA and MONASO working in conjunction with the ministry of health. The activist's visits not only are important for the patients suffering with AIDS but also by enriching contact with the family members and advice about the illness. In so doing they help those who are not sick to know how to support the family members who are infected by AIDS. They become aware of how the disease is being transmitted and reduce the fear they might have by increase their compassion and cooperation for the patients.

It is worth repeating that civic education plays an important role in sensitising people about HIV/AIDS, especially when it's being conducted by an HIV/AIDS infected person. The message has greater impact on the audience because the messengers talk about their own experiences as people who live with the disease.

The home-based care and treatment is very important in many respects. Firstly, it enlightens the family members who are ignorant about how HIV transmitted. Secondly it helps in teaching family members to be compassion to HIV/AIDS patient because the activities are compassionate. It can be agued that the home based care treatment in Mozambique is supplemented by grassroots organizations. So, it is believed that this treatment can become more and more effective and sustainable if grassroots organizations are linked to existing public health services. However, this linkage is not effective because the public health care services are inadequate and insufficient.

The other activity undertaken by these associations in order to sustain them is income generating activities. These include the following:

- Embroidering and weaving different materials for sale
- Selling traditional medicine which is extracted from African potato
- Subsistence agricultural activities

In brief, this grassroots' action and other activities have an impact on PLWHAs by providing secondary income to sustain them.



Figure 11. These members of Kindlimuka Associations sewing staff of selling



Figure 12. *Some member of Thinhena association making vases for selling also*



Figure 13. This picture also is showing a group of women swing

Family: An important source of support for HIV-positive People

People diagnosed with HIV often turn to friends for support, and that's encouraged by doctors and therapists. But Ohio State University research suggests this advice may not go far enough. In Serovich's most recent study, published in the journal *AIDS CARE*, she found that the 134 HIV-positive men were less likely to be depressed if they received support from their families. In another study of 142 HIV-positive men, published in *AIDS Education and Prevention*, she found that subjects who received social support from their families were less likely to engage in risky sexual behaviors than were men who did not get social support from their families.

Serovich does not say that all HIV-positive people should tell family members, nor does she believe all family will be supportive. Some may, in fact, be hateful. So, HIV-positive men should consider seeking guidance from therapists or other helping professionals in making decisions about disclosure to family. And therapists need to encourage exploring those options.

People often need help in figuring out how to disclose their HIV-positive status to anyone, and it's important that they do so. It has been observed that people who disclose their status are more likely to get necessary medical help and find out about clinical trials, new therapies, family support or other options available to them than those who do not disclose their status.

In most cases HIV family members in Mozambique have problems supporting their family members who are sick. This is partly due to lack of knowledge of how to deal with the sick, on the one hand, and to lack of disclosure of those who are sick to their family members, on the other. In fact, many of these HIV positive people argue that it is difficult to inform the family members about their status as well as involving them in the association except in cases where the husband was tested positively and the GATV advises him to bring the partner and this one is also tested positive. But generally speaking families are not involved as pointed out by a member of Esperanca association who once said that

My family doesn't know that I belong to this association. In fact, I never told them ...not even my wife. Because I don't know how they will react (A member of Esperanca association in Quelimane: 2004).

In Chimoio a member corroborates this idea when she says that

I didn't know anything about this disease until my husband who was always sick and had skin problems for years asked me to go with him to the hospital one day. There I was tested HIV positive. He finally revealed to me that he was he also HIV+. This is how we are together in this association (An HIV positive woman in Chimoio: 2004).

This shows how women rarely learn about their husbands' status.

In cases where the woman goes first to the hospital and asks her husband to attend the consultation at hospital this one often responds in these words

You, go if you think you are sick, I'm fine (A member of Thinena support group, Maputo: 2004)

It is clear that the power of the man surpasses that of the woman in Mozambican patriarchal society as such man has a power to influence his wife to go to the hospital and not vice versa.

The anti-retroviral treatment referred to in section (4.4.3.1) requires that family gives support to HIV patients. In fact, when people start the TARV treatment the health service worker obliged them to tell members of their families because of this treatment once started it cannot be interrupted, and these drugs can bring out collaterals symptoms that it becomes therefore important that the family member encourages the patient to go further with it. The counsellors in Maputo association are aware of that as one of them remarks

When people have to start the TARV treatment we require that they come with at least one family member to will be looking after the patient at home. This person needs to be informed about the TARV treatment and its

effects in order to assist the patient whenever he needs help (Officer of MSF, Maputo: 2004).

It is wrong to assume that family support is mostly needed when the patient goes through the anti-retroviral treatment. This support is needed even for orphans (victims left behind by HIV/AIDS deceased parents).

Support for orphans by family network

While we praise Mozambique for its initiative to create its first hospital for HIV-positive children officially opened in Maputo on 24 May 2004 as the country was struggling to cope with more than 30,000 children born each year with the virus that leads to AIDS, we encourage the country to make however a further step. In fact, one of the most devastating aspects of the HIV/AIDS epidemic today is also the growing proportion of children the disease has orphaned. Unlike most diseases, HIV/AIDS generally kills not just one, but both parents. What is more, the stigmatisation and discrimination that people affected with HIV often live with is passed onto their children, making their fight for survival much more precarious.

When parents or caregivers fall sick and die, a child's life often falls apart. With HIV and AIDS, the hardship hits well before children are orphaned. First a parent or caregiver becomes ill with HIV or AIDS, and is unable to work. The entire family feels the economic impact – children, especially girls, must often drop out of school to go to work, care for their parents, look after their siblings and put food on the table. The situation becomes worse, as already said, when both parents die.

If there is one dimension that PLWHA needs to look at very attentively is to develop a system where children can be protected in their environment by the extended families. We believe that African traditional solidarity is naturally a framework that can be exploited and encouraged by governments to take care of children who had lost their caregivers. In this regards, UNICEF believes that whenever possible, children who are orphaned should remain in their communities to be raised by their extended family. Recognizing that family care is far better for children and far less costly than institutionalized care, children who grow up in families also develop better social skills

and are psychologically better adjusted than those who grow up in institutions because they receive more affection and attention and develop a better sense of personal identity (www.unicef.org/aids/index_orphans.html). We totally agree with such an approach, which we believe should be given thought in Mozambique as well by PLWHA.

PLWHA Organizations and fund opportunities

PLWHA & Other Organisations

As already mentioned in chapter 1, the National Response to HIV/AIDS in Mozambique is positive. It passed through several stages. The National Control Programme against STD/AIDS (NACP) was created in 1988, and the first Medium Term Plan (MPT1) was developed. The NACP has a central body, located in the Ministry of Health, and regional offices in 11 provinces. The main responsibilities of the NACP include planning, coordinating, monitoring, and assessing provincial plans, and providing technical assistance to government sectors involved in the program. The NACP also develops short- and medium-term plans and establishes cooperation protocols for Mozambican and international NGOs, donors, and social, religious, and mass media associations. A second Medium Term Plan (MPTII) was developed in 1994. The National Strategy to combat STI/AIDS includes prevention, counselling, epidemiological surveillance, and blood testing. Specific components of the national program include management, information, education and communication (IEC), epidemiological surveillance, laboratory support, care of PLWHAs and counselling, and condom social marketing (Plano Estrategico Nacional).

Organizations in Mozambique such as (MONASO) brought together a variety of organizations working on HIV/AIDS activities throughout the country. MONASO's credit is to have prepared an organizational strategic plan to provide more effective coordination and assistance to local NGOs. With increased disclosure of HIV-positive status, a network of PLWHA has also been formed, and partnerships have been created between the network, other NGOs, and the government

Donors/Funding

Though PLWHA organizations are involved in counseling and psychosocial support, home-based care, training of members, education and awareness activities, these organizations still face various management problems including inadequate technical skills to run their organizations and difficulties in raising funds.

PLWHA in Mozambique have had access to financial supports over years that strengthen and support an expanded response aimed at preventing transmission of HIV, providing care and support, reducing the vulnerability of individuals and communities to HIV/AIDS. But most of the members of PLWHA associations when interviewed refer to finances as the major problem that causes troubles within the associations themselves and their relationships with other institutions. If we consider Elias argument when he says that

We got good relationships with the foreign NGOs; they give us money to develop our activities. The problem is that we don't get that money on time even after the contracts are signed. (Elias at Thinena association, Maputo: 2004).

Such a quote shows that not only these PLWHA associations had nowhere to turn to for assistance, but the PLWHA organizations are faced with organizational problems as well because many members do not have the necessary skills to run the organizations. They need to develop advocacy, fundraising and communication strategies to overcome these problems.

But before we go into all that, let us first remark that multilateral and bilateral donors are actively engaged in Mozambique. **UNAIDS** has a coordinating theme group based in Mozambique since the 1990s. The group, chaired by WHO, consists of representatives from UNDP, UNFPA, UNESCO, The World Bank, WHO, and UNICEF. In addition, major bilateral donors who provide the bulk of AIDS financing in Mozambique are active leaders of the group.

The World Bank supports HIV prevention as part of a road construction project. WHO is carrying out joint activities in the areas of epidemiological surveillance, STI and HIV/AIDS counselling, prevention interventions for vulnerable groups, and blood safety. WHO also provides some direct support to NGOs. UNDP is implementing a comprehensive national AIDS project. UNFPA will support improved integration of STI and HIV/AIDS services into existing reproductive health services in its country program from 1998 to the year 2000. Finland's Ministry for Foreign Affairs, Department of International Development Cooperation, supported a \$1.1 million community development project from 1995 to 1997. The project, implemented by The Red Cross of Mozambique, provided information about HIV/AIDS, nutrition, maternal health care, and hygiene, as well as blood transfusion services.

Pepfar (President's Emergency Plan for AIDS Relief), Mozambican government is now one of the recipients of US President George W Bush's \$15bn Emergency Plan for Aids Relief (Pepfar). But the beneficiaries of Pepfar cash are only allowed to buy drugs approved by the US Food and Drug Administration (FDA). This effectively rules out the vastly cheaper generic treatments that Ms Muhai benefited from. Orla Ryan (2004), BBC News business reporter in Mozambique says that Pepfar represents a healthy injection of cash into the fight against HIV/Aids. Just as importantly, it is the result of US recognition that action is urgently needed.

Private Voluntary Organizations (PVOs) and Nongovernmental Organizations (NGOs)

A number of PVOs implement activities in Mozambique, funded by multilateral and bilateral donors. Some of the major USAID cooperating agencies include The Futures Group, and Population Services International. According to UNAIDS, a relatively small number of NGOs are working on HIV/AIDS prevention and they are concentrated primarily in Maputo and other urban areas. The majority of NGOs receive their funding from external sources and work at a micro level, with limited impact on the epidemic at the national level.

These NGOs, however, do not assist financially unless the associations fulfill certain requirements. This is maybe what the adviser of Rensida (National Network of PLWHA associations) meant when he said that foreign NGOs and donor institutions are tough when it comes to financial support. They give money only when the project submitted to them fits their requirements. Sometimes this is not easy as the organisations have to adjust the project in such a way that it suits them in order to get money. So this kind of relationship is that of dependence. The organisation totally depends on those who have money to function.

This shows that the associations do not have a good dialogue with donors. The organisations have at all cost to accept their conditions simply because they have resources which we do not have. This situation has turned many people to deal with HIV issues depending on how able they are to plan or write a project and not out of real passion for HIV people. People in desperate need of income would go for project NGOs require in order to get finances (Motlhaolwa: 2001: 27-28).

Caution should be taken, however, not to generalize this situation because our research reveals that some international donor agencies are flexible and are willing to discuss and altering the implementation of projects presented by PLWA associations even if it does not fit their agendas.

Accountability is another problem that arises when dealing with financial support issues. In fact, most of these international NGOs demand the associations to give account of how the money given has been used. MONASO and RENSIDA are aware of this problem. Most PLWHA associations struggle with that problem. But it should be admitted that with good managerial skills, integrity, honesty and transparency this is not a big issue. There should be no fear of being accountable to somebody.

On the other hand members of the board of these associations manifest their disappointment in that even though they are given some money by their donors this money does not respond to the needs of the associations with its multitude of activities.

In response to this international NGO's and others institutions argue saying that PLWHA associations are not able to deal with big amounts of money due to the weakness that their administration presents. An officer points out

If they even have problem in justifying that small amount how can we trust them giving more money? (Officer of Action aid, Quelimane: 2004).

The officers are also reluctant as they believe that pumping in a lot of money for HIV/AIDS will not help as the money would be used for other purposes other than fighting against the pandemic. This is confirmed by Ivone who argues:

I don't think that all this money in Mozambique in name of HIV/AIDS is effectively used for the suffering people... there are so many organizations working in on this issue but why is it that the number of infected people increases daily? (Ivone , Maputo:2004).

In Chimoio a NPCS officer adds also that

Something has to be done in order to know really if what all these organizations say is true ... I started to organize the map with all details of each national and international organizations to find out what, where and how they operate in the field (Officer of NPCS, Chimoio: 2004).

As for the president of Thinena association in Maputo

The number of seminars and workshops run in this country and in the world if enough and if the money spent on HIV/AIDS was spent to a productive goal by then this disease could have been already minimized... (President of Thinena association, Maputo: 2004).

For him but the results in the fight against HIV in Mozambique are not satisfactory. According to the Strategic National plan with its new executive secretary it is important that the plan be shifted into another direction. He thinks that in the next few years to pay more attention to the suffering people mainly the orphans. It is in this regard that the CNSC has given more assistance to the orphan programs in the country nowadays.

Still on the front of funds for HIV/AIDS, others complain that they do not benefit from the few that come in for HIV/AIDS programs. The president of Thinena association in Maputo sadly remarks that

There is money for HIV/AIDS program in this country but we continue to die and suffer without food and unable to support our families... where does this money go? (President of Thinena association, Maputo: 2004).

This issue is very complex indeed. But despite all these disagreement between international NGOs and PLWHA associations and the members among themselves as regards funds, the activities of PLWHA cannot be undermined.

This section has shown how the epidemic has now advanced significantly in Mozambique, fuelled by labour migration, rapid urbanisation, high levels of poverty, insufficient health infrastructures and significant rates of sexually transmitted infections.

The Government of Mozambique has taken a robust stance, matched by significant international efforts to combat the epidemic. None of these have so far incorporated large-scale treatment programmes for people living with HIV/AIDS. The emphasis has been on prevention, awareness-raising, voluntary counselling and testing and palliative care.

The author looked at different institutions involved in this fight against the pandemic among which we have MONASO which is the AIDS-NGO umbrella organization funded in 1991. MONASO support the NACP in co-ordinating NGOs and CBOs working on HIV/AIDS activities. Nowadays hundreds of members are working under the guidance and support of MONASO in care and support, training of activists and peer-educators, PLWA, community mobilization, condom promotion and distribution. In each province there is a nucleus of MONASO. The most important activities carried out are: CBOs/NGOs mobilization – co-ordination and support, training for staff members, project design, Media and Government sensibilization and resource mobilization. An international NGO, PSI, is providing also technical assistance to the NACP through the implementation of a Condom Social Marketing (CSM) component.

Some private companies are participating with NGOs to facilitate IEC activities at the work place and are selling the NACP branded condom, JeitO. Around 1000 private sector commercial distributors of JeitO are currently throughout Mozambique. The World Bank & MONASO are in negotiation with many private companies for the obligatory inclusion of STD/AIDS prevention activities for the benefit of the project- workers (and communities surrounded) in the Roads and Coastal Shipping (ROCS) Project. In 1997, the UN Theme Group on HIV/AIDS has invited the chief editors of all major newspapers, radio and TV to discuss the possible roles of media in an effective AIDS program.

The Alliance has been working in Mozambique since 2001 and established a country office in 2003. It offers programmatic and organisational support to local non-governmental and community-based organisations, faith-based organisations, organisations of people living with HIV/AIDS and governmental institutions in the central provinces to respond effectively to HIV/AIDS. It enables orphans, vulnerable children and people living with HIV/AIDS to access quality care and support services through partner programmes in central Mozambique.

Mozambique is battling to contain HIV/AIDS and the government faces hard choices about funds that block access to the cheapest drugs. The Mozambican government is now one of the recipients of US President George W Bush's \$15bn Emergency Plan for AIDS. The fight against this pandemic still continues.

Having thus laid bare all these issues related to HIV in Mozambique, we now feel that the ground has been cleared enough for us to speak of the relevance of PLWHAs in Mozambique based on some history cases.

Relevance of PLWHA in Mozambique discussion

Relevance of the findings

This section is a summary of findings from the review of the author's experience on the work place and interviews with PLWHAs staff and members. Where appropriate, quotes from interviews and documents are included.

The author present first the findings related to the selected History cases's relevance, followed by PLWHAs intervention, their success and effectiveness. The report concludes with a summary of the lessons learned and considerations for the development of these associations up to 2005.

Before examining these history cases, it is important to signal that there are two views regarding the relevance of PLWHA associations: The first view is that these associations are very important because it is only through them that one is able to identify and bring HIV positive people together and assist them. Most HIV/AIDS positive people and national NGOs argue that when HIV people form (recognised) PLWHA associations, this prevents opportunists from getting money in the name people suffering from HIV/AIDS.

The second view, however, is that it does not matter whether there is an association or not because the members that are in the associations are less than the total number of people living with HIV in the country. In other words, not more than 1% of people with HIV/AIDS in the country are in these associations (INE, 2003). Therefore, people would like to see new ways of reaching HIV/AIDS infected people.

In Chimoio, a GTZ²⁰ official argues that:

'It is not important to have PLWHA associations in the country because of the financial costs which include both activities like capacity building and payments of staff members'.

She continues and argues that:

People in the board are the only ones who benefit in these associations and that many women do not see the benefits of being member of the association as they don't have key or high positions in these associations.

²⁰ GTZ it is a German Non Governmental Organization supported by the German government

Surprisingly enough the study shows the existence of GATVs in the cities even though more associations are being formed and expanding through the districts. Moreover, the testimonies of people living with the virus show clearly that these PLWHAs are of great impact in the lives of many Mozambicans if not all.

Presentation of some selected case histories

The focus here is on understanding the appropriateness and clarity of the goals and actions of PLWHAs in order to inform people about their effectiveness. The author analyzed these cases with the following questions in mind:

- Were the PLWHAs appropriate in terms of the needs and the expectations of the HIV/AIDS patients?
- Have they succeeded (at least morally) in assisting their patients?
- Were the planned goals, targets and outcomes clearly linked and comprehensive to people?

The following are some selected case stories of some HIV positive people in the associations. These stories can help us to better understand the problems faced by these people. This is to support the argument that people discover that they are HIV positive when they go to the hospital for other medical examination. Some extracts also elucidate the role played by the family in supporting their dear sick parent. Unfortunately there are examples that confirm that some times they hide their sero positive status prejudicing their partners. All in all situations, PLWHA associations helped these people in various ways to live with this disease without stress.

Case history 1²¹

Elisa aged 31, was divorced 6 years ago and is mother of two children. The oldest is 16 years, the second born is 13 years. The woman is educated up to grade 7. This woman was found at a support group called Tinhena at 1 de Maio hospital in Maputo. She told us her story:

I discovered that I was HIV/AIDS positive because from 2000, I was falling ill frequently. In 2002, I was diagnosed with Tuberculosis and the doctor advised me to undergo an HIV test because he suspected I was HIV positive. I went through the test and the results were HIV positive. I didn't believe the result and as soon as I started to feel better I dropped the treatment. A few months later, I got sick again. So I decided to resume treatment because I thought that I would die if I didn't take the treatment seriously. Now I'm feeling much better.

After getting divorced from her husband she started to work for a private newspaper as a cleaner to enable her support her children. When she fell ill she began to face problems with her employers. Her story continues:

[...] my doctor gave me a recommendation letter addressed to my office saying that I should avoid doing heavy jobs because of my illness. After presenting the letter, I lost my job, because my employers did not have light jobs for me and I was not given any terminal benefits. I took the matter to the Human Rights League of Mozambique. The case is still pending and I do not have any response yet.

I became sick two years after being divorced. I can say nothing about him. No one of my family knows about my situation. I'm afraid to tell them

²¹ For reasons of confidentiality, we will use pseudonyms (not real names) to refer to the people who gave us their testimonies.

because few months ago I lost my sister by the same disease, so I don't want to cause problems to my parents.

I live with my parents and my children. Before I lost my job, I used to help my parents with supporting the family from the little I had as a cleaner. They didn't know that I'm a HIV positive and when I fell sick I told them that I had tuberculosis.

I knew about the existence of this association for people living with HIV/AIDS group through that my late sister. I used to accompany her to this hospital and to this support group. In this support group we are all friends and we are treated in the same way

Case history 2

Jannet gives her own testimony in these terms:

I became sexually active when I was 15 year old. While I was a student I got pregnant and my partner organized the lobola.

When I got sick I was still living with my family and my husband. They took me to a traditional healer who told us that my illness was related to the payment of lobola. But since I didn't get better my husband's family took me back to my parents. Since that time, I never went back to my husband's place because he went to South Africa. But I knew that he was already sick before he left for South Africa. I am convinced having been contaminated by him. He was a polygamist with three wives including myself and had also many girlfriends.

None of us disclosed his/her HIV status to his/her partner, but I think that he started to undergo treatment and use to tell me that we will die together even if we separate from each other.

A few months ago I decided to tell my children that I am HIV positive. This was a way of warning them about the dangers of HIV/AIDS and preparing them to face the challenges of life when I will no more be there. I hope they got my message.

It is difficult for my father to look after us properly. At least he provides food and shelter. But I have to find ways to provide other things such as school fees for my children. I am now working as an activist for this support group. I hope we will have some incentive with time. Till now, we still struggle to find a financial support for our activities.

Case history 3

My name is Elisabeth aged 34 and mother of two children. The oldest is 16 and the youngest 14. I was married till my world was messed up in 98 when my husband died. When we got married, we were young and belonged to the same Christian church. We stayed together for 9 years and it was after that when my husband fell ill. I and his family thought it was a normal disease but he lost a lot of weight. When we took him to Machava hospital, he was found with tuberculosis and was admitted [Machava is a TB specialised hospital in Maputo]. When he felt better, he was discharged from the hospital and came back home. He discontinued his treatment and started drinking heavily. A few months later, he died. After my husband's death I also fell sick and was told at the hospital that I am HIV positive. Then I realised that my husband died from AIDS as well. Two years later, I had a boyfriend who was working in South Africa. I fell pregnant during the time I was there for visit. I thought of my HIV status and I realised that I had to make abortion. I asked my brother to assist me but he denied my request due to his religious belief. As a result my pregnancy grew up until I gave birth to premature twins but who eventually died.

Although I was ill during my pregnancy, my situation, however, became worse after I gave birth. I fell seriously ill, I had TB and herpes zoster. I went back to the hospital but the nurse was disappointed. She sadly remarked that I was not supposed to be pregnant knowing that I'm HIV positive. I apologised for my gaffe.

It was at the hospital where I found friends who introduced me to Tinhena association. I am now feeling better and taking the medication consistently. I love to be here because of the warmth atmosphere of friendship between us. I come here everyday. It is here where I find friends with whom we talk about our lives openly and support each other. We are comforted by the idea we have the same problem.

I am now living with the father of my late twins who also was tested HIV positive. I explained my status to him and he accepted to take an HIV test. We are living together without any problems. When I started the anti - retroviral treatment the nurse asked me to come with a family member. I took my father. (This is a condition for starting this kind of treatment in all hospitals). My husband's father helps us to support the family because both of us are not working.

Some of my family members know my HIV status but I have never told others about it.

While this story seems to have a happy ending, not all of them do.

Case history 4

My name is Jorge. I am 34 years age and have never been married but I used to have a lot of girlfriends. I stay with my brother, my sister-in-law and my nephews. My brother is the only one who is working. It was in 2000 that I started feeling that I was sick. While ago in South Africa I used to work as a security guard in a company in Gemirsten and had that privilege of going to the hospital for treatment. Despite these good efforts, instead of improving my condition was worsening. This is how I ended up loosing my job and was given money, just enough, to travel back home. In Maputo my family took me to traditional healer in Gaza province but there is no improvement.

The first and serious disease I suffered from in my life was a sexually transmitted disease. The hospitals in South Africa failed to solve

this illness. When my brother took me to the hospital I already had a lot of complications. Besides, I developed herpes zoster and lost a lot of weight. I was unable to move by my self.

I was asked by a medical doctor to undergo an HIV test and the result was positive. I was admitted and transferred to hospital “1 de Maio”. Before I started with my treatment, I was already left with 34kgs only. What a loss! I was put on an anti retroviral treatment which I have continued to take till now. Nevertheless, I regained weight and weight 68kgs now. I know for sure that HIV/AIDS is real. I have this disease because of having many girlfriends, many sexual partners. I was never concerned about safe sex. I trusted all of them, I never used condoms. See what happened now!

I was invited by the coordinator of the support group to attend the meeting after consultation with the doctor, and I joined this group. I learned quickly that that I was not the only person on earth with this problem. This is how I started attending meetings every week. Now I also invite other people to join our group.

No one in my family knows that I am HIV positive apart from my brother who took me to the hospital, therefore, I have never been discriminated against by any of my family members or neighbour what ever.

As activists we have a project to visit fellow HIV positive people at home, we are not receiving any incentive but we hope that we will start receiving that very soon. If we had some incentive, that would be good for us, we would be able to look after our families and continue to work without worries.

Discussion of Findings (case histories)

These examples of case histories are what one should consider as revealing the reality of HIV/AIDS in Mozambique. These examples also may put to rest any argument that PLWHAs are not doing a proper job in Mozambique. They prove beyond any doubt that

PLWAs associations give real support to HIV positive people in this country. These case histories, moreover, represent and continue to represent several cases of HIV peoples bad and good experiences all over the country.

In the first interview (and many others that come after) Elisa shows how she only went for an HIV test when she realised that she was seriously sick. Like her in Mozambique most people realise that they are HIV/AIDS positive only when they frequently fall ill and are advised to take an HIV test. Based on our interviews 100% of people in the associations knew about their situation because of the persistent illness. The author is, therefore, tempted to generalise that people in this country never decide to have HIV test before they can experience illness. Yet having HIV test before one is seriously sick can increase chances for one to protect himself. Researchers suggest that the proper strategy for battling AIDS is to attack the virus. Most researchers, however, believe that the best approach is to treat HIV early, since this may preserve the body's own defenses against HIV.

Reading Jannet's story in interview 2 makes the author at first glance to think of polygamy as one of the main causes of HIV infection in Mozambique. In Mozambique, HIV infection increases because husbands who usually have a number of sexual partners. It is often to hear of stories like this by Stephanie Nolen (2005) about Azarias Mateusse and his four wives. *It has been four years since they buried Azarias Mateusse in the crowded cemetery in Xai Xai, but his shadow still looms large over the little concrete house where he lived with his wives. His first wife, Anita Manhiça, 43, is rail-thin and racked by a bone-shaking cough. These days she lies on a straw mat in the dusty yard, with barely the strength to tug a faded cotton sheet around her shoulders. She shivers, although it is 30 C. Azarias's second wife, Alba Houhou, 31, is starting to feel unwell. Some days she hardly has the energy to get dressed. She sends the children to fetch water from the village standpipe. And his third wife, Gracinda Invane, 33, has read the signs at Azarias's house; she has taken her two children and moved into town. But Gracinda, too, most likely has AIDS.*

Jannett is one of those victims in a polygamous marriage, whose marriage makes her end up HIV positive. Polygamy is the most frequent and main mode of transmission of HIV. Most HIV positive persons in this country have up to four partners (if not wives).

Another issue is that Jannett has been able to reveal her HIV status to her kids. In fact, deciding who to share your status with not only is a very personal decision but also a very difficult one to take. It may be hard to know if telling certain people will bring good or bad consequences. You might fear negative responses like rejection, discrimination, abandonment, or isolation. You might worry about being judged or feel guilty about past drug use or sexual behavior. In some situations, revealing your status could put you at risk for physical harm. Since some people may not be as accepting of your HIV status, these are all valid issues to think about.

Telling kids about one's status is not a practice which is common in Mozambique where it can be associated with taboo. If you have kids, telling them about your HIV status can be even more challenging. It is like telling them about other touchy topics -- such as body parts, puberty, and sex issues. But telling them can sometimes be rewarding.

Because on the Children with infected parents are a growing group who have concerns of their own: "Who will take care of me if my parents get sick? What happens to me if they die?" So, it might help them to start imagining their own destiny in this world without parents. But this depends on age since the youngest ones (0 to 10 year old) have nothing to do for themselves.

The National Women's Health Information Center (2005) writing about *Women and HIV/AIDS* acknowledges that there are mixed opinions on how mothers should handle this difficult decision. It provides however the results of some studies which show that open communication about the illness to their kids is better than not telling them. Children may already know something is wrong; keeping the illness a secret can confuse children and make them feel anxious. Other studies, the center argues, have found that children have negative reactions to being told, like behavior problems, sexual risk-taking behavior, and lower school performance. Several studies have shown that if a HIV+

mother reveals her status, telling a child to keep her health condition a secret is stressful for that child and as a result, that child may have behavior problems.

In one study, women with HIV who told their children about their illness were interviewed. They recommended these tips for talking to your kids about your HIV status.

- Think about why you want to tell your children. Make sure you're ready.
- Educate yourself about HIV so you can talk to your children about the illness.
- Plan for what you're going to say.
- Consider how healthy you are. It might be better to talk to your child when you're feeling healthy and can show your child a healthy, positive attitude.
- Think about other things going on in the family. It may not be the best time to tell your child when there are other stresses in the family.
- After you tell your children, get them additional support. They could talk to a health professional who can talk more with your children about HIV.

With regards to the above, we see that it took Jannett a lot of courage to reveal her status to her kids. It is left to the reader to see where, when, how, why, and whether or not do the same once found in the same circumstances.

The author is provided with other encouraging issues by *Elisabeth Ricardo* in interview 3 whereby the speaker who supposedly contaminated her husband with the virus encourages him to confirm it with a test and the later surrenders. The author is also encouraged by the example given by both families supporting them even as *Elisabeth* started her antiretroviral treatment.

Unlike most cases where they have portrayed women as sexual objects by African men, here *Elisabeth's* example forces us to believe that African men are not all unreasonable. An HIV positive man can also make his partner understand that although she might be

the cause of his misery but he does not blame her for his own mistake for having not undergone with her for test before marriage. This makes the author also to believe that all the myths, stereotypes around African men being abusive can be challenged though still happening here and there. Gender equality has been firmly on the transformation agenda in Africa. Values such as respect of women's dignity and opinions are now recognized and getting ground.

Family support as, already discussed, is very important for HIV positive persons. *Elisabeth* example is of many which show that African people are good in providing practical and emotional support to their family members in pain no matter how the disease was contracted. (e.g. individuals living with HIV or AIDS). What they need maybe is a frame where a range of special services or training to those affected by their loved ones having HIV or AIDS so that they can now what exactly to do when the subjects undergo treatment, how to handle them.

In Interview 4 *Jorge* goes for traditional leaders to cure HIV/AIDS. It was also observed that some of the respondents consulted traditional healers at the same time that they are undergoing treatment in their respective hospitals. It is still believed by some people in Africa that HIV is caused by witchcraft or sorcery therefore *Sangomas* (traditional healers) or traditional healers are the only ones who can handle or solve such problems. This is easily rejected by science which believes that HIV disease has nothing to do with spirits intervention and therefore see it as a merely body disease. Whether this African belief is based on metaphysical dimension is a result of their ignorance or not, it remains, however, true that some people confess openly that traditional treatment is worth it.

AIDS action (2004) argues that 'western' or 'modern' medicine can reduce levels of HIV in the body and treat HIV-related opportunistic infections, but many people with HIV have no access to even the most basic western medicines. It is estimated that in many developing countries, particularly in rural areas, four out of every five people visit traditional health practitioners and use traditional treatments.

Traditional healers already treat large numbers of people living with HIV and AIDS. It is important to look at approaches to working with traditional health practitioners that can

improve HIV prevention and care services, while continuing to advocate for improved access to western medicines and treatment.

Some programs have trained traditional health practitioners in HIV/AIDS and other sexually transmitted infections (STIs). Appropriate training encourages traditional health practitioners to replace harmful practices or myths about HIV with safer practices. It can also help them to diagnose HIV and other STIs and encourage increased collaboration with biomedical or 'western' health services. This collaboration can have a number of advantages and biomedical health practitioners also need education in the benefits of working with recognized traditional health practitioners. For example, traditional health practitioners often have an approach to healing that takes into account the whole person - their mental, emotional, spiritual and physical health. Initial research into a variety of traditional treatments also suggests that some of these treatments offer potential relief from HIV-related infections; although like western medicine, none of these treatments is a cure for HIV.

This issue proper referring of *AIDS Action* looks at some successful approaches to working with traditional health practitioners and using traditional health practices to improve HIV prevention and care.

The traditional healers should be perceived as educators. This is so because respected traditional health practitioners see many clients and they can be very powerful educators. They have influence in the community, as well as with other healers through their professional networks. They understand local belief systems and can explain illness and misfortune in ways that people understand. It is important that they have correct information about HIV/AIDS and other sexually transmitted infections.

This paper argues that many people with HIV approach traditional healers even when they have access to other health services. One reason is that traditional healers usually treat the 'whole' person, not just the disease. They take into account a person's mental, emotional and spiritual as well as physical well-being. This can include contacting the spirits for help.

Traditional health practitioners often see their patients together with other family members and can play an important role in family counseling and in reducing stigma and discrimination against people with HIV/AIDS.

A quick look at these stories also revealed that what most of them share in common is that they often fail to disclose their HIV status (except to one case story). Most of the people interviewed confirmed that they did not tell any one of their family members that they were HIV positive until they started taking ARVs. This problem is related to discrimination and stigma. Similarly all complain about poverty and being unable to look after their family.

Finally, they all acknowledge the help they got from the support group or PLWHA associations. This frame provides a contact point and meeting place where HIV people get together and talk through their thoughts, fears, worries and frustrations without being faced with the stigma associated with the illness.

In short, people living with HIV/AIDS (PLWAs) can live positively with HIV longer if they talk openly about their problems and share information with others. Keeping HIV a secret could make those who are infected feel unhappy and stressed. Such emotional stress weakens the immune system. Disclosing (sharing) one's HIV status with someone else can help people get counseling, and help them get connected with others who are HIV-positive and able to provide support. In addition to people with HIV attempting to talk more freely, the entire community and religious leaders can contribute to the fight against HIV/AIDS by avoiding stigmatizing those with HIV and cooperating with each other to address the problem.

Conclusion

In this chapter the author has shown how HIV organizations have developed from support groups into associations. This was out of the need of becoming formally structured, be legally recognised by the ministry of justice and also to reach more people. It was believed that only associations could achieve these goals. The feelings, sentiments and desires of HIV people or PLWHAs members, their struggles and happiness in life both as individuals and members of PLWHAs were clearly expressed and presented in

this chapter. Most importantly, among their problems lays their need of being accepted in the society. The social responses of fear, denial, stigma and discrimination which have accompanied the epidemic for a while need to be dealt with. HIV people should not be denied access to the services and treatment they need. In Mozambique where HIV and AIDS are believed to bring shame upon the family or community, we insisted that good policy or law should help combat HIV/AIDS related discrimination.

Gender inequality was raised as one of the main cultural issues related to HIV in African and particularly in Mozambique. In this chapter, the have provided an overview of the gender-based abuses in this country that fuel the HIV/AIDS epidemic and make the lives of women and girls already living with HIV/AIDS unbearable. The argument was based largely on the horrifying stories told by women and girls who have suffered abuse from their husbands and in-laws. Through stories and voices of the women and girls and through research, the report illustrates the inter-linkages between human rights violations of women and girls and the HIV/AIDS crisis. It is hoped that an understanding of the human reality of these abuses will lead to greater protection of the rights of the girls and women at the center of a deadly epidemic.

The also spoke about fund raising. PLWHAs struggle to have funds though some efforts made by donors such as World Bank and others to support them. In fact, the author recommend that those HIV organizations (PLWHAs) that are serious about fund raising must also be committed to developing a rapport and reaching out to potential donors. Building relationships with donors, potential donors, local community and local government are essential. The more these organizations are kept informed, the higher the chances are that they will continue their support. The author also suggested that honest communication between the organizations and the donor can improve the lives of the sick people.

The author ended this chapter with case histories where analysis was made on some testimonies of HIV +people. It has been observed that people living with HIV/AIDS (PLWAs) can live positively with HIV longer if they talk openly about their problems

and share information with others. Keeping HIV a secret could make those who are infected feel unhappy and stressed.

CHAPTER 6 - CONCLUSION

Recapitulation of key issues

HIV/AIDS is a new holocaust that reaches all people independently of race, religious, sex, age or social position. The consequences of HIV/AIDS can be far-reaching for young people. Not only does HIV disease have terrible consequences for the individual, causing serious illness and eventual death, it has the potential to trigger negative social reactions. Across the world, people with HIV/AIDS routinely experience discrimination, stigmatization and ostracization.

The intrinsic problems posed by this pandemic constitute a new challenge. The increasing number of people infected by HIV/AIDS in the world has forced the infected people to be organized in groups or associations in order to face together the challenges of living with HIV/AIDS in the society.

The associations of PLWA and its members face many problems such as discrimination and stigma that is attached to the scourge. But notwithstanding these problems, these associations are showing an incredible dedication to addressing the issue of HIV/AIDS.

In Mozambique, the associations have specific and unique problems that are linked to the realities of the continent. These problems include poverty, illiteracy, cultural stereotype and many more. Despite the fact that many associations, in Mozambique as in other parts of Africa, are experiencing difficulties; some associations have done very well in their work. For example, the South African and Ugandan associations have so far demonstrated that they are capable of defending the interests of their members. For Mozambique, however, there seem to be no definite improvement to HIV/AIDS issues in Mozambique despite the good work which is undergoing there under the PLWHAs. The legal future of this population is unpredictable, it is less certain, but the author believes that, at least for the therapeutic aspect, a big part of HIV population, efficient comfort from these PLWHAs associations has been obtained.

In the three provinces where this research was conducted evidence revealed that the associations of PLWHA are a new phenomenon, where the members are looking for their own space in order to tackle the problem that is being posed by HIV/AIDS.

This research tried to disaggregate the experiences that are pertinent to these associations and give a voice to people in these associations. Most of the time, matters of HIV/AIDS have been ranked as least priority. This investigation of PLWHA associations which was conducted in three different geographical areas in the country showed more similarities than differences. These differences and similarities were within the association itself, the day to day running of the association, and the relationship of these associations with government institutions and civil society.

The study found three major modes of heterosexual transmission, transfusion and mother to child. The risk factors are: poverty, migration (miner), population movements, refugee return from countries with high HIV prevalence, high prevalence of STD in young people, resistance to condom use, economic dependence of women, and also lack of information, illiteracy and disbelief.

The research reveals, furthermore, that there are no significant differences between HIV/AIDS associations in these three provinces. There are more similarities than there are differences. They share in common unemployment, low level of schooling, uncontrolled urbanization, prostitution, lack of resources to support their family members, etc.). Other types of similarities are shaped by patterns of formation of these associations which were similar and may have been formed by the same people. However, in Maputo which is the capital city, due to the favourable conditions there, these associations and support groups are more developed and dynamic than in other provinces. It would however be interesting to find out how HIV/AIDS positive people in rural areas are responding to the problem of HIV/AIDS.

It is also worth remarking that HIV geographic distribution is uneven in the country. Central provinces (Manica, Tete, Sofala, and Zambezia) are more affected than the Northern and the Southern Provinces. The trends follow the major transport routes and the areas bordering Zimbabwe, Malawi and Zambia. In these areas of the country, many

factors, in the past, have contributed to increase HIV/AIDS infection and other are fuelling the spread of the epidemic (unemployment, low level of schooling, uncontrolled urbanization, prostitution, e.g.).

The study also found much variation or inequality between men and women around the issue of sexuality displayed by gender roles. For women and adolescent girls, the consequence of AIDS can be particularly dire. There is strong evidence, for example, that in African countries (e.g. Mozambique) women are often "blamed" for HIV disease even in circumstances where they have been infected by remaining faithful to their husband or other male partner. There is also evidence to suggest that women are less likely to receive the kind of care and support made available to male household members (Warwick et al., 1998). Moreover, where the male head of household has died there is sometimes loss of social support for young women, ostracization from the community, and lack of legal protection to inherit land and property.

The gender inequality is mainly confirmed by the reaction of men towards HIV test. It is said that when a woman is diagnosed with HIV/AIDS first, she does not get support from the husband or his family because the tendency is to blame her for contracting the disease and she may end up being returned to her parents. On the contrary, if the disease is detected first in the man, the wife will normally support him till his death even though she may be accused by her husband's family of bewitching the husband.

This study found that HIV positive women face difficulties when it comes to following the teachings of vertical transmission programmes because they lack the capacity to feed their babies with artificial milk. They feel obligated to breast feed their children because their families expect them to do so. In this regard, women are faced with difficult decision of disclosing their HIV status. On one hand, if they disclose their status they face the risk of being chased from home and, on the other hand, they face the risk of transmitting the virus to the baby if they breastfeed their child.

In Mozambique there are two different types of associations of people dealing with the problem of HIV/AIDS. These include support groups and PLWHA local association. Support groups are the informal groups that are not legally recognized by the Ministry of

Justice, while PLWHA associations are formal organizations and are legally recognized by the government. Nonetheless the objectives and most important activities are the same in both forms of organization. Most members joined the associations and support groups after being invited by the other members working as activists in hospitals.

This research argues, however, that lack of adequate knowledge about HIV/AIDS, fear of infection, the stigmatization, put these associations at a disadvantage in coming out to speak about their HIV/AIDS status and its associated problems.

This research accepts also the fact that members in these associations are firstly concerned with gaining material and financial support although sharing experiences and mutual consolation among members remain the ultimate goals. Most members of these associations are people who have HIV and are who lack economic means to have a better living. Therefore they are weak and have problems with performing their jobs.

The income-generating activities run by these associations are not sustainable because of stiff competition. There are too many NGOs doing the same income, generating activities making it too hard to market products produced. Another weakness is that they lack initiatives and the capacity to negotiate with donors for long term sustainable project.

The context of poverty, dependence, superstition, illiteracy, unemployment, violence and an overall sense of doom plays a role in sexuality and sexual and interplay amongst the poor, shaping their responses and, as shown in this thesis, their inability to protect themselves in the face of this pandemic. This highlights the fact that HIV/AIDS is a different reality for the rich and the poor people. In this regard, poor people in these associations do not have the means to support themselves and their families, while rich people have means to themselves and their families and can afford treatment in private clinics.

In Mozambique prominent citizens living with HIV keep their status hidden and are not involved in HIV/AIDS information awareness campaign in the associations of PLWA. This could be because of the fact that HIV/AIDS is seen as a disease for poor people. The

stigmatization of HIV/AIDS has become so high that people infected with the disease deny any association with this epidemic.

It was also realized that rich people experienced confidentiality with issues relating to HIV/AIDS when compared to poor people. This is because while poor people have to go the associations to deal with his/her reality, rich people have options of private clinics.

It should be added that poor members of PLWHA associations regard themselves as near death since they do not have access to antiretroviral drugs and other resources. They believe that their way of life changes after being diagnosed HIV positive they feel discriminated against and alienated by their families and their communities.

It was also discovered that most members of the associations did not disclose their HIV/AIDS status to their partners and families. They behaved as though they are not HIV positive and continued to have many partners. Women continue their reproductive cycles and breastfeeding despite attending the PTV Programa de Transmissao Vertical 'Transmitted Vertical Program' where they are through how to avoid the vertical transmission. The reason behind is that the fame of having a baby or being called mother of *xx* or *xy* (baby's name) is in Africa much more valued (even if the baby eventually dies later) rather than not having one.

This study showed that there are more women than men in PLWHA associations because women are found to have HIV/AIDS virus when they attend consultation related to their reproductive health. Women in these associations normally do not assume high positions and therefore it is difficult for them to address their major concerns. Men usually occupy executive positions. The traditional attitudes of gender inequality which consist in men always occupying dominant positions are reflected in the associations.

The research also showed that family members bear the burden of caring for the sick and their dependants and have the potential to do so even though they are sometimes failed by their limited resources. When a family member is HIV positive, it entails a high burden on his family because they have to support him/her under high level of poverty, increasing unemployment, deterioration of household income, and rising cost of living,

and poor coverage of health services. But there is sometimes little involvement of family members in the activities of PLWA associations due to lack of information. And some get interested only when their family members are about to start ARV treatment as required by PLWHA. Before a patient begins with his/her ARV treatment, a member of the family has to be briefed on the consequences of undertaking this treatment.

It is sad to remark that the increasing number of *GATVs* in the country is not accompanied by increasing level of knowledge of the HIV/AIDS pandemic. The number of people who undertake voluntary testing for HIV/AIDS is insignificant. Moreover, the only service provided is HIV/AIDS testing for people suspected of having the virus by the hospital.

Mozambique is passing through a difficult time in that beside the HIV/AIDS pandemic, the Government has to deal with other national issues which divert government attention on the problem of HIV/AIDS. In addition to the above, the adoption of the new liberal policy to reduce the intervention of the state in social welfare, health, and education impacts negatively on the fight against HIV/AIDS. Nonetheless the government does intervene on a small scale through the CNCS and the Ministry of Health. This is illustrated by increasing number of *GATVs*. The approval of antiretroviral policy is a good example of the interventions of government although many people also die from the treatment's side effects.

These findings revealed that the relationship within associations and between the various stakeholders is not always harmonious. Weak partnership among NGOs working in the field of HIV/AIDS, competitions for funding, and disagreements among the members of these associations are some of the problems that hinder the successful implementation of HIV/AIDS programmes. Most of the associations acknowledge that their organisations are weak and that; they lack human and financial resources to efficiently and effectively implement programmes. However the National networks of HIV/AIDS has made efforts in trying to solve this common problem jointly in the last few years.

Recommendations

On basis of the findings of this research, the author would like to make the following recommendations:

Given the fact that less than 1 % of People Living with HIV/AIDS in Mozambique are members of these associations, there is a need to do more work to integrate more people in these associations by mobilising people under VCT and, if they are found HIV positive, to encourage them to have access to associations, or perhaps even compel them to join as a condition for receiving ARV treatment.

HIV health care services and activities of PLWHA association should be extended to people affected with HIV/AIDS in the rural areas.

Government, civil society and the media should step up its efforts of reducing discrimination and stigmatization of PLWA through information campaigns. They should also redesign the messages in the information campaigns to ensure that they reach achieve the targeted audience, and add messages that promote PLWA associations and the benefits of joining them.

It is important to have a national welfare policy which will mitigate the problems of people infected and affected by HIV/AIDS. Particular attention should be paid to vulnerable groups like children who have been orphaned as a result of losing parents through HIV/AIDS. The government should take the responsibility of supporting HIV/AIDS positive women by providing milk and other food for their babies until they have grown up. Above all, reducing poverty should be one of the effective ways to deal with HIV/AIDS.

Prominent citizens in Mozambique should be mobilized to take an active role in the fight against HIV/AIDS. If they are infected they must come in the open and declare their status and get actively involved in the associations of people living with HIV/Aids in Mozambique. By doing this they will change the mentality of poor people who view AIDS as a disease for poor people.

NGOs and CBOs should strengthen their internal organizational structures and broaden their networks through forming partnership with other NGOs dealing with this issue. The increased efficiency in terms of service delivery and partnerships will strengthen their collective voice and make it easier for them to share resources, to work with other non-NGOs actors, and to lobby with the Ministry of Health Ministry and other institutions.

The author would like to call upon the government of Mozambique to increasingly involve PLWA in responding to the HIV/AIDS pandemic.

The government in conjunction with other stakeholders involved in the fight against HIV/AIDS should come up with a strategy that will encourage its citizen to undergo routine voluntary testing and counseling for HIV.

Government in conjunction with other stakeholders involved in the fight against HIV/AIDS should be more efficient and effective, thereby reducing the negative effects of bureaucracy. The government should mobilize more resources so that all HIV/AIDS infected people may have access to ARVs.

Given the challenges of the HIV/AIDS epidemic, the government and civil society need to pay attention to the plight of these families who usually have limited resources and are faced with the task of dealing with this problem.

The challenge of associations in Mozambique, therefore, is to recognize these weaknesses and to find means and strategies for overcoming them in order to reduce the impact of HIV/AIDS in the country.

Significance of Findings

These findings have significance for the discipline (anthropology) because they show that although much progress has been made to integrate HIV issues into our discipline, but much more still needs to be done. As a whole, anthropologists need to work much more effectively to produce, and publish more about HIV/AIDS. The findings also illustrate great differences between the creation and maintenance of PLWHA associations. There is a great discontentment from the members as regards to the management as they believe

that those in positions of power misuse the money. This money does not profit everybody. The author is of the opinion that this claim is worth consideration and that those engaged in business of HIV organizations need, and would consistently be, more concerned about the well-being of those whose rights and needs they claim to defend. A 'poor' quality service hosted by a business such as this one can generate immediate negative feedback from HIV people. If these poor people continue to express their dissatisfaction with services offered they may feel penalize both sides by the disease on the one hand and mentally and emotionally on the other hand.

Limitations and Future Research Opportunities

This study has hinted at a number of research areas which merit further study. In the area of retroviral treatment, it would be helpful for there to be an ongoing effort to evaluate whether this treatment helps or does not help Mozambicans. Researchers need to see on a continuing basis the side effects of these drugs. Another issue is that of structures that need to be put in place for HIV children or orphans left behind by parents who died with HIV to grow from with family love.

The idea of extended family that needs to be supported financially as they might wish to foster these children is a great idea but which requires further investigation. We think that PLWHA need to include such a project in its program as well. Surely there will be improvements and even greater improvements in the future if this project is given thought.

There should be additional research work to compare the PLWHAs operational, and informational enhancements of HIV education programs in urban areas with those operated by these organizations in the rural areas. The lack of knowledge or information in these rural areas demands it. Yet, the current research has illustrated areas in which the PLWHAs services are more advanced although it did not cover the whole country. Perhaps additional research work with larger populations would help in this regard.

There is clear evidence that PLWHA well-designed programs of sex education, which include messages about safer sex as well as those about abstinence, may delay the onset of sexual activity, and reduce the number of sexual partners, and increase contraceptive

use among those who are already sexually active). Here again, further ongoing research is warranted to see to what extent sex education's applications are important for HIV positive and negative people.

The current research has barely scratched the surface of what is obviously a concern of many international donor Institutions and NGOs. A reading of the written survey responses by our interviewees shows that there are clearly many financial problems related to mismanagement of PLWHAs or lack of transparency as far as the funds are concerned. A clear relationship has already been established between PLWHAs and their international donors on HIV issues; they must continue to build this relationship (foundation) so that it can save the lives of millions of people hit by the virus. How can the structure be altered as to meet the objects originally designed for the associations? This is the question that must constantly be asked and addressed to the stakeholders and more especially the leaders of the PLWHAs.

All these issues are important in a general sense in that their investigation will help us better explain our world and the people living with the virus. But the issues are critical to the future survival of the PLWHAs associations, which have themselves been threatened in many ways in the recent past. If we are to be the true researchers that Africa needs, we can possibly be in the research effort we make along these lines that must continue and be able to create effective strategies now to fight against HIV/aids in the years to come.

In short, the research effort was limited initially by a lack of theoretical development in the literature. Previous works did not provide enough linking materials on HIV to The case study of PLWHA, its creation and maintenance of its programs as evidenced by the interviews. While the methods used here are reliable, and the means of measurement appear valid, the concepts involved have not previously been investigated elsewhere and should be subject to further study.

This research was not intended to make claims about discussing the entirety of all the problems pertaining to HIV disease. Rather, the research was aimed at making generalizations about HIV as dealt with by PLWA associations in Mozambique, how they help those who are infected and affected by HIV. This research supports the work

that PLWHAs association do save lives of people. Whether PLWHAs have succeeded or not is another issue and the reader may draw his/her conclusions from the work.

Recommendation for further research

It could be important to find out how other HIV/AIDS positive people out of the associations follow the life of these associations. The institutions dealing with this issue have to investigate how they can work with other informal associations based in the communities and religions. To extend the study at level of rural areas, as a way to explore what the local institutions do in this context. Why these associations are only concentrated in the cities? As we live in the time where people migrate from rural areas to big cities in search of better opportunities of life will not be the cities invaded once more by HIV if considerable efforts are not made to contain the disease both in the cities and rural areas? Further studies are needed to explore all these areas. Above all as Monteiro suggest is important to accept the perceptions of multi voices approach in this matter of HIV/AIDS in Mozambique.

This study revealed that a number of significant socio- cultural factors had an impact on HIV/AIDS situation in the three provinces. But it didn't gather evidence showing how these different factors impact in HIV/AIDS context. For instance data from INS Instituto Nacional de Estatistica ' National Institute of statistic' concerning to HIV/AIDS prevalence in the three regions of the country, indicate that the Northern Region has a low level of prevalence. It may be important to undertake a study in this region where Muslims are predominant.

It would also be interesting to find out why other HIV/AIDS positive people are not members of these associations dealing with the problem informally and not through associations, for example at household level, community level, church level etc.

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<http://www.napwa.org.au>

Appendix

(1) List of Acronyms and Abbreviations

AIDS- Acquired Immune Deficiency Syndrome

AMODEFA- Associacao Mocambicana do Desenvolvimento da Familia

CBOs- Community Base Organizations

CEA-UEM- Centro de Estudos Mocambicanos Universidade Eduardo Mondlane

CNCS- Conselho Nacional de Combate ao SIDA

FDA- Food and Drug Administration

FDC- Foundation for Development of the Community

Frelimo- Front of National Liberation Movement

GATV- Services of Counseling and Voluntary Testing

GTZ- German Technical Cooperation

HIV- Human Immunodeficiency Virus

ICW- International Community of Women Living with HIV/AIDS

INE- National Institut of Statistic

Kindlimuka- A National Organization of People Living with HIV/AIDS

MISAU- Mozambican Ministry of Health

MONASO- Mozambican Network of AIDS Service Organization

MPT1- Medium Term Plan

MSF- Medicos sem Fronteiras

MULEIDE- Mulher Lei e Desenvolvimento

NACP- National AIDS Control Program

NAPWA- National Association of People with AIDS in South Africa

NGOs Non Governmental Organizations

NPCS- Provincial Nucleon Against AIDS

PLWHA- People Living With HIV/AIDS

PLWA- People Living with AIDS

PMA- World program for Food

PNUD- Programa das Nacoes Unidas para o Desenvolvimento

PVOs- Private Voluntary Organizations

RENAMO- Movement of National Resistance

RENSIDA- National Network of Associations of People Living with HIV/AIDS in Mozambique

SAT- Southern Africa AIDS Training

SIDA- AIDS

STI- Sexual Transmitted Disease

TARV- Ante Retroviral Therapy

TASO- The AIDS Support Organization in Uganda

UNAIDS- United Nations Agency for AIDS

UNDP- United National Development Progr am

UNDP- United Nations for Development program

UNICEF- United Nations Children's Fund

USAID- United States Agency for International Development

VTC- voluntary Counseling and Testing

WHO- World Health Organization

WLWA- Women Living with AIDS

Guide of the interviews for the different target group

Specific questions directed to members of the board of the associations

Here major emphasis was put on understanding the many issues that can be divided into 3 sections, as follows:

- What has motivated the creation of the associations? Who, how and when they were created?
- How do they do function?
- What type of structure do they have?

The way members adhere to the associations as well as the membership requirements; member's rights (benefits) and obligations; their funding sources; the way associations interact,

Both in the country and outside.

- Difficulties encountered (relationship among members and with other members of the civil society, governmental institutions and financial support).

PLWHA who are members of the associations

Concerning this target group, it's maybe also important to find out what actually motivates people to join those associations.

- In what circumstances and how do they learn about the association's existence and mission?
- Why do people become member?
- What are the advantages and disadvantages in being a member of such kind of association?

- Do they receive some kind of advice?
- Are their family members aware of their individual membership status towards the associations?
- How do their family and other members of society in general react to this situation?

Officers of the local and international NGO's dealing directly with these associations:

- When did they start working jointly with these associations?
- What kind of partnership do they develop with these associations?
- Do they develop specific activities? What kind?
- What are their impressions about PLWHA's associations?
- What are their major difficulties in dealing with the associations?
- Apart from these associations, which other partners do they have?
- What are the differences between the associations?

Governmental institution's representatives working with the associations

It is perhaps important to get to know the government's position towards matters related to People Living with HIV/AIDS in the country, because they are the most important decision-making bodies. It seems also relevant to find out the kind of strategies they draw on in dealing with the HIV/AIDS pandemic, particularly with people already suffering from AIDS. Questions including:

- What kind of support do they give to the associations?

- What are the challenges being taken by the government towards minimizing the impact of the disease?

What type of activities do they develop in these contexts?

**A Comparative Study of Associations of People Living
With HIV/AIDS in Mozambique: The case of Maputo,
Manica and Zambezia provinces**

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A dissertation Submitted at School of Social Anthropology, University of Witwatersrand,
Johannesburg, in Partial Fulfillment of the Requirements for the Degree of Masters of
Humanities and Social Sciences, Department of Anthropology

Johannesburg, 2005

Declaration

This thesis is entirely my own work and has not been previously submitted as a research project, dissertation, or thesis, at any other University

.....

Elisa Maria da Silveira Muianga

January 2006

University of the Witwatersrand

Dedication

To my children Neusa Tania da Silveira Chitsonzo and Ivan Maximiano da Silveira Chitsonzo and my parents.

Acknowledgements

I would like to thank to my supervisor Prof. Robert Thornton for his guidance during the elaboration of this thesis.

I would like to extend my gratitude to all my professors at the Department of Anthropology, WITS, for the high quality of their instruction during the course.

I also owe a particular debt to my family especially, my father who always been a source of support. My mother, sisters, colleagues and friends, whose moral support and love made it possible for me to complete the course.

Deep thanks go to Rensida staff, PLWA Associations (in Maputo, Chimoio and Quelimane), MONASO, CNCS, FDC, Hospital Dia and others in (Maputo, Chimoio and Quelimane) for providing me helpful information for this study.

Thanks to all members of the different associations of PLWA in Mozambique especially those located where I carried out the study in Maputo, Manica and Zambezia province.

I would like to thank Kellogg's Foundation and AED for the scholarship and research fund that made it possible for me to realize this thesis. I could not be happy without addressing my thanks to CEA/UEM, the institution that gave me the opportunity to continue with my studies.

Abstract

This study was inspired by the need to develop awareness about what is going on in Mozambique regarding to the issue of HIV/AIDS. The research examined how and why the organizations of PLWA (People Living with HIV/AIDS) in Mozambique are emerging and developing, compared the particularities of the existing organizations of people living with HIV/AIDS in three province of this country (Maputo, Manica and Zambezia), and finally examined how they function, and interact with governmental and non- governmental institutions.

The study made use of the ethnographic method to design and generate a rapid "picture" of the social culture around this HIV community. The focus on this method provided further in-depth qualitative insights. Behavioral surveys were designed to provide rapid key data on sexual behavior, condom use and STI¹s. Together, these sources of data provided a spatial, quantitative and qualitative overview of the research.

The results from this study turned that the associations of PLWA and its members face many problems such as discrimination and stigma that is attached to the scourge. But notwithstanding these problems, these associations are showing an incredible dedication to addressing the issue of HIV/AIDS.

In the three provinces where this research was conducted it transpired that the associations of PLWHA are a new phenomenon, where the members are looking for their own space in order to tackle the problem that is being posed by HIV/AIDS.

The research reveals, furthermore, that there are no significant differences between HIV/AIDS associations in these three provinces. There are more similarities than there are differences. The associations have in common issues such as unemployment, low level of schooling, uncontrolled urbanization, prostitution, lack of resources to support their family members, etc. Other types of similarities are shaped by patterns of formation

¹ Sexual transmitted infections

of these associations which were similar, what invites one to think that may have been formed by the same people.

As combating HIV/AIDS seems an important tool in poverty eradication, Government, civil society and the media should step up its efforts of reducing discrimination and stigmatization of PLWA through information campaigns. They should also redesign the messages in the information campaigns to ensure that they achieve the targeted audience, and add messages that promote PLWA associations and the benefits of joining them.

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CHAPTER 1 - Scope of the Research

HIV 'community'

Our world today is one in which organizations are designed and created as tools that help those living with HIV/AIDS. It is one of the greatest challenges for our times. The fact that biomedicine has not been able to come up with a cure for AIDS has aggravated the association of this disease with stigma, discrimination, denial, shame, fear, silence and death.

HIV/AIDS: Acquired Immune Deficiency Syndrome (AIDS) is the result of an infection with the Human Immunodeficiency Virus (HIV). This virus attacks selected cells of the immune, nervous, and other systems impairing their proper function.

According to UNDP every 6 seconds, someone becomes HIV positive. The increasing number of people infected daily by HIV/AIDS in the world has, on the other hand, pushed people organize themselves and put into place existing structures to help to some extent people living with HIV/AIDS. (PNUD: 2004)

Mozambique has one of the highest HIV positive rates in the world. About 16, 2% of the adult population (15-49 years) is estimated to be HIV positive. There are about 500 new infections per day. About one million of people are HIV positive (MISAU: 2005).

This constitutes a large HIV community, that like others communities such as ethnic, economic, religious, found reasons to organize themselves to respond their eminent needs.

In this study, the term 'community' means first 'HIV community'; and being a member of it has different meanings in a practical sense to different people. To some it means people living with the virus, to others it means all those who are interested in HIV issues, while to others it means organizations such as PLWHAs.

PLWHAs understand their membership in terms of rendering specific services to the community or giving financial, moral or intellectual support.

Aims of the research

The aim of this thesis is to examine how and why the organizations of PLWA in Mozambique are emerging and developing, compares the particularities of the existing organizations of people living with HIV/AIDS in three province of this country (Maputo, Manica and Zambezia), and understand how they function and interact with the governmental and non- governmental institutions. The present study also seeks to document the impact of the disease on people relationships, by looking at how the subjects of the study interact with other socio-cultural organizations such as families in their lives. Another important aim of the study is to map the experiences of the associations in the three provinces studied, as a way to understand the subjects' experiences (those living with HIV-AIDS into the associations) in Mozambique.

In short, this thesis seeks to show how the subjects of the study battle with HIV and difficulties inherent in this struggle through the associations that support them. It is in this context that author seeks to give voice to those people who have been marginalized by their HIV status and stigmatization.

Research questions

In support of the research aims formulated in the paragraph 1.2, the following research questions will be researched.

- How and why the organizations of PLWA in Mozambique are emerging and developing?
- What are the similarities and differences among organizations of people living with HIV/AIDS in the provinces of this Maputo, Manica and Zambezia?
- How do these organizations function and interact with the governmental and non-governmental institutions?

- What is the impact of HIV/AIDS on people relationships, concerning to how the subjects of the study interact with other socio-cultural organizations such as families in their lives?
- What are the experiences of the associations in the three provinces studied, concerning to dealing with people living with HIV-AIDS in Mozambique?
- How do the subjects of the study battle with HIV and difficulties inherent in this struggle through the associations that support them?

Benefits

If readers and researchers explore the nature of research questions fully:

- The research project has more chance of fitting in smoothly with the plans of this association;
- Other associations and researchers are likely to learn from the process as well as the outcomes of research projects; and
- These associations, the government and researchers will be able to consider the implications of research for practice over a longer period.

Theoretical Framework

The topic of this thesis concerns organizations of people living with HIV/AIDS in Mozambique. This topic could be viewed within the framework of “civil society” which could be complemented by the others concepts such as social movements. Considering that this study was been done in Mozambique where the PLWA associations fall in the category of NGOs, the concept of NGOs will be also discussed.

Controversially, it has been observed that there are several conceptual definitions of civil society. Which entities what should be considered as civil society and its relation to the state? This concept is contested. Social scientists too have a problem defining civil

society in a precise and concise manner. The concept has attracted different perception and meaning. In other words, there is no consensus on the exact meaning of the term. In this study the Kaviraj's definition can fit well, when he argues that civil society is "an organized institution standing outside the state's legal *jurisdiction*, which undertakes and finds a response to specific matters within the social, political economic domains". (Kaviraj *et al*, 2001). In this perspective, different kinds of organized groups of people such as associations can fall in this category.

This concept of civil society can be reinforced by embracing the another key concept, that of Social Movement, understood as a collective action, made by an informal group(s) of people of different social categories usually excluded from history who begin asserting themselves as historical actors. Normally they are committed to broad change at the levels of individual behavior, social institutions and structures. Examples include social movements of women, ecologists, gays and others which have played a role played in social and political changes through the world.

In this regard the HIV/AIDS community can be seen in the category of excluded group considering the deep stigma and discrimination associated with this disease.

Altman argues that according to the level of organizations and commitment these movements can achieve important goals. He took the example of a gay movement that managed to influence governments and the society to develop a sense of identity among its members. (Altman, 1989:30).

The organizations of PLWHA in Mozambique can be regarded as a way of responding to specific matters of concern in the world by a group of NGOs (NGO is an acronym for non-governmental organizations that cover a whole range of organizations from e.g. small local environmental pressure groups to large international human rights organizations).

- They must be non-violent groups.
- They must not want to replace the incumbent government- they should not be political parties or opposition groups.

- They should support the aims of the organizations which recognize them (Berg, 1998: 12).

The movements of civil society play an important role in the fight against HIV/AIDS. However, attention should be given to the fact that a civil society is not above in this battle. In Uganda, for instance, they work side by side with governmental institutions. The country's authority calls for full involvement of CBOs, NGOs, donors and religious institutions (Thornton, 2003a; 2003b).

Controversially, in South Africa, the civil society, in the context of HIV/AIDS, appears to be an opposition force to the government, and puts pressure on the government to force it to pay more attention to this concern. In Mozambique civil society pleads with the government and complements the work of the government.

Using this theoretical framework, I will analyze, examine and assess their effectiveness of the role of these organizations in the context of Mozambican civil society.

Given the wide spread of HIV/AIDS in the world, and Africa in particular, the number of organizations dealing with this pandemic especially associations of people living with HIV/AIDS is increasing everyday.

This phenomenon, which opens ways for '*groups directly affected to organize themselves*' (Goss *et al*, 1995: 6), can in some way be justified by the relatively limited government intervention. The UN's secretary general, Koffi Anan assumed this same position during an interview with the BBC News answering to the question on whether he was winning the battle against HIV/AIDS, his response was that: "*I am not winning the war because I don't think the leaders of the world are engaged enough*" (in <http://www.news.bbc.co.uk/2/hit/Africa/3244564>).).

People living with HIV/AIDS seek to organize themselves in associations as a way of sharing their difficulties, fighting against common enemies, giving each other emotional and spiritual support and practical assistance (Kaleeba *et al*, 2000). That is why the author personally found it important to undertake this study and see to what extent the existing three associations of PLWHA in Mozambique follow the objectives above.

Mozambique has got three PLWHA organizations so far. In mid 1990's the first one was created in Maputo city. A few years later, two other associations emerged in Chimoio city (Manica province bordering with Zimbabwe and in Quelimane city (the Zambezia central province), respectively (MONASO²: 1999). These associations operate only in the province's capital cities.

As a Mozambican, I have interest in undertaking this case study because in Mozambique, according to available reports, stands among the sub-Saharan countries with the highest number of people infected by HIV/AIDS. However, the number of associations of people living with this infection in the country is assumed to be far less than expected; in addition to this, most people likely prefer not to adhere to those associations, or even to be aware of the advantages of being a member. The fear of being discriminated and stigmatized by the society could be the most important reason.

This study will assess the importance of these organizations dealing with PLWHA.

Methods and techniques

This study was undertaken following a *qualitative ethnographic methodology*. This methodology was adopted because the study is an exploratory study. It examined specific sites, comparing small groups in order to bring out perceptions of the people involved in these organizations and their major concerns, such as:

- The people's motivations for creating the organizations of PLWHA in Mozambique
- The functioning or organizational structure PLWHA organizations
- The organizations funding sources, and
- Their major constraints

² MONASO is a network of HIV/AIDS organizations in Mozambique. It incorporates all sorts of organizations dealing with HIV/AIDS.

The study brings together the perceptions of the people involved in these organizations and their major concerns.

This research was conducted in Maputo, Chimoio and Quelimane cities in Maputo, Manica and Zambezia provinces respectively. It is in these three provinces where the first associations of people living with HIV/AIDS PLWHA were located. This specific task was to observe the way associations interact in their respective offices and/or clinics. It also gave the opportunity to look at the ways they deal with their members including their common problems.

Along side this method the research also includes the combination *semi-structured, open-ended interviews*. *Semi structured interviews* were administered to the board members of local and international NGOs as well as government institutions. *Open -ended interviews* for members of the associations and *case studies* were also recorded from some people living with HIV/AIDS in the associations.

Participant observation during fieldwork was the principal method for data collection. In short, a *multimodal approach* was an effective strategy towards strengthening the sources' reliability.

Fieldwork and procedures

The first step of the fieldwork was to make arrangements with the umbrella institutions based in Maputo which directly deal with associations of PLWHA at national level. In this way, four institutions were first contacted:

1. Rensida *Rede Nacional de Pessoas Vivendo com SIDA*, an umbrella organization that is working with associations of PLWHA.
2. MONASO, 'Mozambican Network of AIDS Service Organization' that includes national and international NGOs dealing with HIV/AIDS issues.

3. CNCS, *Conselho Nacional de Combate ao SIDA*, 'National Council on the Fight against HIV/AIDS' is a governmental institution which coordinates all activities related to HIV/AIDS at all governmental, civil society and private sector levels.
4. Ministry of Health which supervises all issues related to public health including the HIV/AIDS pandemic.

This strategy enabled me to have a picture of what these associations have been doing in the context of HIV/AIDS in Mozambique on the one hand, and to make arrangement for later contact from there with the associations and others institutions targeted for this research, on the other hand.

After this step I came to the second step of *in-depth interviews*. In Maputo I interviewed a number of the governmental institutions such as Ministry of Health, Ministry of Woman and Coordination of Welfare, Hospital dia and CNCS. All these institutions were also contacted at provincial level. All interviews were taped for transcription.

In the process, I also dealt with NGOs both national and international. One or two officers from each of them were contacted. The selection was done according to the level of involvement in HIV/AIDS issues. From HIV associations, however, I interviewed two staff members, the president or the executive director or secretary, or both of them, depending on their availability. In the provinces five members of the same associations who were targeted responded as well to the requests. The number of National and international NGOs in each province varied from one province to another. The majority of them were contacted whenever they were referred to the author by others during our interviews.

It is important to observe that this study was possible only in the capital cities of the provinces for the simple reason that the districts do not have associations of people living with HIV.

In Maputo were in total 25 interviews with HIV-AIDS positive effective members of the associations including case histories of NGOs, national and international, and five governmental institutions. Similarly, in Quelimane two interviews were conducted with

HIV associations, ten HIV positive members belonging to both existent associations. Three International and three National NGOs were contacted as well as the three most important governmental institutions at provincial level: Health, Women and coordination of Welfare and CNCS National Council on the Fight against HIV/AIDS.

In Chimoio were contacted two associations made up of twelve members, six in each association. Two international and three national NGOs were contacted. The same governmental institutions contacted in Quelimane were also visited and contacted in Chimoio.

Given the nature of the study, it was not easy for some people to respond to the interviews for fear of discrimination and stigmatization. In Maputo, for example, in one of the support group I was asked to reveal my sero status – to determine whether I was like them, since this would make them comfortable during the interview. Skhosana confirms how difficult is to conduct study in this perspective. According to her, she found specific strategies in that moment to deal with her research (Skhosana: 2001)

In Manica province I was asked by two young people to be paid for having been interviewed. It has been a practice for some researchers to pay the interviewees. However I did not pay informants for information.

Special problems arose during the fieldwork in all studied provinces when some associations (i.e. members of the board) of HIV people were the ones who decided which people should be interviewed and which not. Without their mobilization it was not possible for me to find people for those interviews.

All in all, the fieldwork covered a period of three months. It should be acknowledged that all was done successfully but not without some obstructions. I quickly learned an important lesson that a researcher even in her own country should not assume that the interviews will be transparent and unproblematic. As a field worker I was, also able to learn more than the scope of the research itself. I was able to notice laughter, reprimand, correction through which I had to see how people living with HIV socialize or fail to socialize with others.

Constraints

Language or communication barrier was one of the difficulties I had in the field, but not a major one. In cities where most people speak Portuguese, I chose Portuguese as a language for communication. However, some HIV positive were more confident speaking in their native languages, I solved the problems through interpreters.

Photographs were taken to document some findings and they added support to the data collected. Verbal consent of participants was sought before photographs were taken. Some of the informants did not allow pictures, fearing that I could sell their images.

Ethical considerations

Given its delicacy, this research topic has a lot to do with informant's intimate life and privacy. Interviews were conducted in a careful manner, following the principles of respect and confidentiality according to the WITS University's statement of principles and the American Anthropological Association's statement of Ethical principles for Anthropology. I made our informants aware of the research's purpose, which is to seek and contribute to further improvement of the associations of PLWHV and their memberships and obtained verbal or implicit consent. In learning about others through active participation in all steps of my fieldwork, I learned for example, in this context of HIV, those who were suffering from it, I tried by all means to make them feel free and more comfortable despite their status. I also protected their identity as professionally required for an anthropologist researcher. In short, respect and confidentiality were the most important requirements considered during the fieldwork.

Structure of the work

In **Chapter I** of this work, a brief overview of the topic is outlined. The Introduction identifies also the scope of the study of PLWHA 'People Living with AIDS'. The concept of civil society and social movements are discussed. The principal techniques used in the research, are described.

Chapter II gives a broad picture of HIV/AIDS in Mozambique. After years of colonial rule, civil war, floods and famine, Mozambique is now considered one of the world's poorest countries with one of the highest HIV infection rates – 13.6% of 15-49 year olds are HIV positive. This chapter gives a picture of PLWHA organizations in fighting against HIV/AIDS and helping HIV people.

The literature review is the main concern of **Chapter III**. This section provides the sources cited throughout the work. It offers information on the range of other studies cited and how they influence this work. I include work of scientists in other disciplines, such as bio-medical, psychology, and culture. The literature cited in this section shows how HIV/AIDS issue is the concern of everybody and not just anthropologists.

Chapter IV is about presentation of the three provinces in study. The general idea of these provinces related to the location in the country as well as the population is given. Some socio- economic indicators are shown in the context of specificities of each provinces. Factors that would influence the prevalence of HIV/AIDS are presented. On the end there is presented the PLWA organizations in each province and a brief history of their creation and function.

Chapter V deals with the presentation and analysis of results. This results section contains the **data** collected during experimentation. It is the heart of this paper. In this section, much of the important information is in the form of translated interviews. Tables and graphs of characterization of members of the associations of PLWA are also given.

The **Conclusion VI** re-states clearly and concisely the key issues covered in each of the main points in the body of the text, and provide a concluding statement that integrates the ideas presented there.

CHAPTER 2- BACKGROUND INFORMATION ON HIV/AIDS IN MOZAMBIQUE

Country profile



Mozambique



Fig. 1 Map of Mozambique country
([http // www.worldpress.org/ profiles/ Mozambique](http://www.worldpress.org/profiles/Mozambique))

The population of this country is approximately 18 million people where more than 99% belong to indigenous ethnic groups. The ratio of men to women is 96 to 100. Forty-two percent of the population is under the age of 15. (INE: 2000)

Mozambique is considered one of the world's poorest countries, and all of the country's social indicators are well below sub-Saharan African averages. Mozambique's ten-year civil war reversed post independence improvements in basic services and had a major impact on mortality and morbidity, especially among children. Thirty to forty percent of Mozambique's children are chronically malnourished. Roughly 60 percent of the population still lack access to health services. The Mozambican government now allocates 8 percent of its current budget—about US\$2 per person per year—to the health sector. (INE: 2000)

During most of the civil war, the government was unable to exercise effective control outside of urban areas, many of which were cut off from the capital. An estimated 1 million Mozambicans perished during the civil war, 1.7 million took refuge in neighboring states, and several million more were internally displaced. In the third FRELIMO party congress in 1983, President Samora Machel conceded the failure of socialism and the need for major political and economic reforms.

In December 2004, Mozambique underwent a delicate transition as Joaquim Chissano stepped down after 18 years in office. His newly elected successor, Armando Emilio Guebuza, has promised to continue the sound economic policies that have encouraged foreign investment.

Part of the poor conditions in Mozambique is a heritage of Portuguese colonization, because under this regime, educational opportunities for black Mozambicans were limited, and 93% of that population was illiterate. In fact, most of today's political leaders were educated in missionary schools. After independence, the government placed a high priority on expanding education, which reduced the illiteracy rate to about two-thirds as

primary school enrollment increased. Unfortunately, in recent years school construction and teacher training enrollments have not kept up with population increases. With post-war enrollments reaching all-time highs, the quality of education has suffered. However this has improved after independence (Serra: 2000).

HIV/AIDS in Mozambique

HIV/AIDS is one of the greatest threats to the development of Mozambique, kills people in their productive and reproductive years. This pandemic has a responsibility to increase the vulnerability of the families associated with the increasing of numbers of orphans in the country. Health and education services are losing skilled staff, reducing the provision of these services.

According to the MISAU, Ministry of Health and the INE the epidemic situation of HIV/AIDS in Mozambique by province and by the three regions in 2002

Province of Mozambique	Prevalence %	Prevalence %/ Region
Niassa	11.1%	8.4% North region
Cabo Delgado	7.5%	
Nampula	8.1%	
Sofala	26%	16.7% Center region
Manica ³	19%	
Tete	14.2%	
Zambezia	12.5%	
Maputo city	17.3%	14.8% South region
Maputo province	17.4%	
Gaza	16.4%	
Inhambane	8.6%	
Mozambique	13.4%	
Mozambique actually	16.2%	

Table 1 HIV Prevalence by Province. Source: MISAU: 2002 and 2005

According to MISAU pointed that in 2001 about 56.600 adult people have died by AIDS
Concerning the life expectation according to the projection, in 1999 it was 43 years; 2004 46.4 years and in 2010 could be 50.3 years without AIDS. However the life expectation

³ The provinces in red are that in study

with AIDS in Mozambique at the same periods was 41 years; 38 1 years and will be 35.9 years with AIDS, respectively. (MISAU: 2005).

For the surprise of Mozambican the recent data of Ministry of Heath indicate that the current national prevalence 2005 is 16.2 %. Half of the people living with HIV/AIDS (PLWHA) in Mozambique are between the ages of 15 and 29. Girls and women are at especially high risk and are being infected at a ratio of two to one over men. In 2004 we had 470,000 orphans due to HIV/AIDS in Mozambique. Currently, we have more than this figure, which will increase to over one million orphans by 2010. (MISAU: 2005). Extreme poverty, urban and cross-border migration, unequal distribution of power between men and women, stigma, and low literacy levels fuel the HIV/AIDS epidemic.

The first AIDS case was reported in Mozambique in 1986. The country's HIV prevalence rate is lower than the rates of neighboring Zimbabwe, Zambia and Malawi, largely due to the isolating effects of the civil war.

The scale and future impact of HIV/AIDS in Mozambique can only be understood by examining it in relation to its young population. Youth, aged 10-24, comprise 34% of Mozambique's population, and youth aged 15-24 account for 60% of new HIV infections in a country estimated to have a HIV prevalence rate of over 12% (MISAU:2005) .

Although the isolating effects of a ten-year civil war kept the HIV prevalence rate in Mozambique lower than the rates in neighboring countries, it is still one of the nine countries in Africa hardest hit by the epidemic: Given the increasing number of people suffering from HIV/AIDS the Mozambican government has approved antiretroviral therapy (ATR) and diagnostics policy in the country. But the costs due to the rising number of persons living with HI/AIDS will overwhelm an already existent health care budget. Prevention activities focused on young people, the mobile population, better quality and coverage of voluntary counseling and testing services. The actual cost of ARV treatment per patient is 250 USD per year what means that the government has to expend too much money only for this matter while malaria tuberculosis, cholera continue to kill more than AIDS (CNCS: 2005)

In short, Mozambique is a country where people have seen all. The Mozambique Liberation Front, or Frelimo, formed in 1962 by Eduardo Mondlane, Frelimo sought to completely liberate the country from Portuguese rule. The war lasted over 10 years, effectively ending in 1974 when the fascist regime was overthrown. The independent Republic of Mozambique was proclaimed on 25 June 1975:

Then troubles really began. The drought and famine of 1983 also brought the country to its knees. In January 2001, floods killed about 700 people, left half a million homeless and devastated the economy. Some of the flooded areas - and many others besides - were then hit by a drought the following year. The economy remained crippled by debt, with annual payments almost twice the public health budget. Above and overall the country is fighting against HIV/AIDS today.

NGOs and HIV/AIDS in Mozambique

The NGO sector in most countries like Mozambique led the early responses to HIV/AIDS issue. There are many different typologies and classifications of these NGOs. However we can distinguish two: national and foreigner NGOs that specifically dealing with AIDS called by AIDS services. Normally these organizations are members of MONASO and RENSIDA national umbrellas of organizations dealing with HIV/AIDS and of PLWA respectively. Since the end of decade 80 local NGOs of PLWA started emerging and integrating these two umbrellas.

These organizations in general focus their activities mainly on the following areas:

- Prevention of sexually transmitted diseases and of HIV/AIDS transmission among young people through school awareness programmes;
- Fight against discrimination, stigmatisation and marginalisation of people affected by and infected with HIV/AIDS;
- Support of families caring for relatives living with HIV/AIDS;
- Care for children orphaned by HIV/AIDS.

- Advocacy for ARV treatment
- Few of them in partnership with the government provide ARV treatment

The increasing number of PLWA members enlarged the “HIV community” that wanted to organize themselves. Similarly, the increasing disclosure of HIV- positive status has led to the formation a national network of PLWHA, as already indicated in the introduction, which works in partnership with other organizations and the government. The RENSIDA (National Network of People Living with HIV/AIDS was created in 2000.

In this Network are included PLWA but mostly who are member of HIV/AIDS associations. The most important aim of this National network is to stimulate the formation of self-help groups of local People Living with HIV/AIDS, to coordinate and support their activities, and to help bring them together in one voice. This network for PLWHA receives financial support from SAT, UNICEF, Action Aid and ONUSIDA (interview with secretary of Rensida ,2004: Maputo)

The association known as *Kindlimuka* ‘wake up’ in the local Ronga language is the oldest of the PLWHA organizations in Mozambique, founded in 1996. Based on Kindlimuka’s experience, thirteen other associations of PLWHA have been established in others provinces. The formation of these associations is behind National and Inetrnational NGOs as well as governmental institutions such as services of blood and GATVs. (services of counseling and voluntary test)

These associations have as main tasks:

- Providing counseling, home -based care and inc ome generation activities including the production and sale of clothing and material for construction.
- Organizing education on how to prevent HIV/AIDS for young people aged 13-18 years in schools. Testimonials by association members on their sero-status have become an effective tool used to reduce stigma and to increase awareness.

- Identifying vulnerable children and families caring for orphans, with involvement of community leaders.

RENSIDA is an umbrella organization. It is a Non-Governmental Organization, which integrates all organizations of People Living with HIV/AIDS in Mozambique. Activities implemented by RENSIDA with the UNICEF complement each other. UNICEF has been supporting institutional capacity building of RENSIDA through technical advice, training, and the provision of material and equipment. RENSIDA developed a national strategic plan and operational plans of the associations in 11 provinces for 2004. In addition, UNICEF has been supporting community monitoring projects for orphaned and vulnerable Children through RENSIDA in fifteen districts in Gaza (Kuvumbana), Manica, Sofala, Tete and Zambézia provinces

CHAPTER 3 - LITERATURE REVIEW

HIV/AIDS as a social phenomenon

Today, as in the past, those who write about the issue of HIV/AIDS emphasize the role of people living with HIV as infectors rather than those who are infected to such an extent that this view is widely accepted as "common sense." In public health initiatives, the "public" appears not to be concerned about how to help these people who contracted HIV to live a better life of stigma, rejection and marginalization, and also help them not to disseminate or transmit the virus to others – innocent people and children considered to be potentially innocent victims of AIDS, at the expense of others like prostitutes. But, in so doing, writers promote oppression of HIV positive people and impede the struggle against HIV.

The first cases of HIV/AIDS in the world were associated to the homosexual people and drug users so people in the heterosexual life were not concerned about this disease.

Today many people blame prostitutes or sex workers. Generally, women and men working in the sex trade have been considered as vectors for transmission rather than persons who, for many reasons, including legal reasons, are vulnerable to contracting HIV. But most recently, the evidences show that every one is susceptible to be HIV positive independently of their sexual orientation. Related to HIV/AIDS indicators in Africa, are handicapped by inadequate means of confirming diagnosis, on the other hand the high sickness rates contribute in a large way to obscuring the true prevalence of HIV/AIDS in many African countries (Agadzi, 1989: 92). HIV/AIDS cannot be seen anymore as only a bio-medical disease. "Specific social and cultural patterns such as the sexual networks, the availability of needles, the political and economic power relationship of prostitution, the nature of transport routes areas of high prevalence are factors showing the social face of this disease" (Altman, 1994).

As Altman remarks that no illness in human history has generated so many meetings, so many scientific publications, nor so much political rhetoric and government response Altman, 1994:2) as HIV/AIDS. In fact, a number of articles trace the history of

HIV/AIDS (Altman, 1994; Macks, 1987; McAdam, 1996; Agadzi, 1989; Corr, 1994; Cad & E, 2002). Though different resources have been consulted in the frame of this research, this work, however, has heavily drawn on the research conducted by Altman's *Power and Community: Organizational and Cultural Responses to AIDS*, 1994 that discusses various HIV/AIDS organizations. It shows how other forms of responses to HIV did not successfully help those who live with the virus and how, most striking of all has been the response from those most affected by the epidemic itself. It strengthens the idea that without strong community-based responses the best meaning of public health systems will fail to deal with the crisis of AIDS. For Altman "one of the major goals of the community-based movement has been to slowly drag public officials to recognition of the multi-faceted needs of an appropriate HIV/AIDS strategy.

HIV/AIDS and vulnerability of poor people

Altman recognizes that the HIV spread and its social consequences are closely linked to the dislocations of economic and social 'development' and, in West, to the growth of particular sub-cultures and regimes of sexuality. In other words, a single approach the study of this pandemic cannot help; it needs to be approached from various angles, including cultural and economic aspects. According to PNUD (2004) 39.4 million people are estimated to be living with HIV 25.4 millions can be find in Sub Saharan Africa. The increasing number of people with AIDS in Africa mainly in Southern Africa, for example, allows us to associate this disease with poverty. Obviously, the people of this region are most frequently infected because of their life conditions (Altman: 1994).

Lancet (2004) in Preventing HIV/AIDS through poverty reduction remarks that the association of poverty with increased HIV prevalence does not necessarily indicate a causal relation. But for him, explanations have been offered at several levels as to how poverty may increase susceptibility to HIV/AIDS. He has also argued that poverty increases biological susceptibility to HIV/AIDS in the same way it does many other infectious diseases. When he refers to the malnutrition, parasitosis, and lack of access to health care among the poor, suggests that these factors undermine the integrity and immunity, and increase the likelihood of having other

untreated sexually transmitted infections. All of these influences can increase susceptibility to HIV infection and progression.

Of significance in this debate is also the fact that poverty is not alone in its destruction. It is also often associated with lack of education, and illiteracy can mean that messages regarding risk and prevention are inaccessible. These authors continue to argue that even with knowledge of the risks; the cost of prevention may be prohibitively high because many poor people are unable to afford condoms. Poverty also restricts people's choices and leaves few options but to undertake high risk behaviors. It is in this context that in Lancet (2004) also identified poverty-driven labor migration and commercial sex work as activities likely to increase HIV infection.

Thus, poverty is one important factor in increasing susceptibility to HIV/AIDS, and facilitating its spread. HIV/AIDS also increases poverty, at all levels from individual to nation, through its impact on working age populations. The morbidity and mortality among this age group affects household incomes, and is a major challenge to the ability to deliver services such as education. It is important to recognize, however, that there are many other influences besides poverty acting to facilitate the spread of HIV/AIDS. Income and gender inequalities are likely to be as important as absolute poverty, as shown by the high prevalence of HIV/AIDS in countries with large inequalities. Other challenges include finding the political will to combat the epidemic, and the stigma associated with HIV/AIDS.

With respect to this debate two conclusions to be drawn from the above observations. First, since poverty plays a role in creating an environment in which individuals are particularly susceptible and vulnerable to HIV/AIDS, poverty reduction will undoubtedly be at the core of a sustainable solution to HIV/AIDS. Therefore, investment in equitable poverty reduction efforts must continue, even in the face of other pressing needs. Second, since poverty is clearly not the only factor contributing to the spread of HIV/AIDS, there is no excuse for taking a fatalistic attitude to the epidemic, in which little can be done until some utopian poverty-free ideal has been achieved. We can concur with Lancet, and others that social factors such as poverty, gender inequality and illiteracy

are closely related to HIV/AIDS increase and need to be studied deeply, reduced if we have to succeed in our fight against HIV in Africa and Mozambique in particular.

There are more studies relating HIV/AIDS to poverty specifically on household of developing countries. Desmond and Gow advance the view that the capacity of vulnerable household and communities to respond to the economic, social, and health impact of HIV/AIDS on their households are weakened ever day due to extreme poverty. women and children are the most seriously affected “ that is why anthropology has the methodological tools to study the social experiences of those who are afflicted by this disease while simultaneously keeping the humanity of those who are infected in the professional discourse on AIDS” (Desmond & Gow, 2002:19).

HIV/AIDS pandemic as already stated above required the involvement of community-based organizations because other groups which existed before these did not include those most affected by the epidemic. In Latin America people place stress on the concept of civil society and the need to strengthen it. In this work the stress is on the civil society which we believe can help organizations of people living with HI/AIDS such as PLWHA. Like Altman, we believe that the importance of intellectuals in the largest sense may help communities make sense of meanings of AIDS. Hence the emphasis on anthropological intervention in this research which puts high demands on social and cultural aspects of HIV/AIDS.

Countrywide organizations of PLWA

National Networks of People Living with HIV/AIDS worldwide are becoming more and more powerful acting on behalf of all people living with HIV/AIDS. The oldest national AIDS network organization in the world was found in the USA, in 1983. According to NAPWA, too little attention has been paid to the very real issue of meeting the prevention needs of people living with HIV/AIDS. The best strategies for preventing new HIV/AIDS infections should engage people with HIV/AIDS as partners, but it is also important to consider that people living with HIV/AIDS are extremely heterogeneous, and programs need to address the different needs of such a diverse group: Race, gender, sexual orientation, age, language, geography etc.

People Living with HIV/AIDS in the world are been organized themselves as a way to respond the epidemic rather than being blamed for the epidemic or regarded simply as its unfortunate victims. So HIV positive people have been valued as one of the society's most important assets in coping with the effects of the pandemic and preventing its further spread.

The global Network of PLWHA is a world network for and by people with HIV/AIDS. It is based in Amsterdam, Netherlands, and has a board of 12 members representing the various international regions. The overall aim of GNP is to work towards improving the quality of life of people living with HIV/AIDS. This can be achieved through the capacity building of people with HIV/AIDS.

According to Williams (1995), PLWHA associations in general, have the following objectives: (1) psychological care, (2) emotional support, (3) medical treatment and nursing, (4) information, (5) material assistance, (6) acceptance and non-discrimination. As mentioned above, the association's primary objective is to support people living with HIV/AIDS and their family members. It could be in terms of moral or economic support. Some of them provide community and home care assistance. Their membership is mostly impoverished people, thus limiting their capacity and effectiveness in advocacy. This also reflects the existing social stigmatization against them from the moment they reveal to be HIV positive or AIDS patient. This is a real situation in Mozambique. In different parts of the world, for instance in Uganda where HIV/AIDS awareness is high and greatly supported by the civil society, there are national networks of this kind of associations.

The examples of Uganda and South Africa

Organizations of PLWHA worldwide enface the problem of discrimination and stigma, but given the increasing number of infected people and this kind of associations they are fighting these issues with a relative success. This has proved true in Uganda through the TASO Organization of People Living with HIV/AIDS and NEPWA National Association of People Living with HIV/AIDS in South Africa where they have been extremely important in shaping their society's response to HIV/AIDS.

In fact, Uganda's response to HIV/AIDS has been comprehensive therefore is seen as a model for the rest of Sub-Saharan Africa. Since 1992 HIV prevalence in Uganda has dropped by more than 50%. The involvement of government institutions, the civil society as well as numerous community led initiatives could be the most important factors for decreasing HIV/AIDS in this country.

(www.cdc.gov/nchstp/od/gap/country/uganda.htm)

Organizations like TASO (The AIDS Support Organization) and Phill Lutaya initiatives strive to put a "*human face to HIV/AIDS*". So ordinary citizens associated AIDS with real people then their own risk perception increased and turn were more receptive to campaigns for safer sex. (www.aidsugand.org/pdf/role-of_vct.pdf)

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Authors like Fieldman and Carter add that successful battle against HIV/AIDS in Uganda can be also associated to the government policy strategy consisted in empowering women giving them the voice in first person. On the other the encouragement to bring out people in good status to talk about their sero positive status was helpful to combat the stigma. (Fielman & Carter, 2003).

NAPWA's international programs works to combat the HIV/AIDS epidemic by advocating for the needs of people living with HIV/AIDS and promoting the active engagement and leadership of PLWHA established partnership with other parts in the world, specially in Africa and the Caribbean countries. There are many National networks of PLWHA in the world, for example, PLWA in Australia which advocates on

behalf of people living with HIV/AIDS. This umbrella works with government researchers and pharmaceutical services. (<http://www.napwa.org.au>)

In Africa, for instance, we can take the cases of South Africa and Uganda, whereby such national networks seem to be well established. The success of South African NAPWA movement had to do with the strong experience of *civil society*. This has been able to draw on the organizational and advocacy experience of the anti-apartheid movement as well as the gay and lesbian movement. It attracted educated individuals and professionals as well as poor and marginalized people (Centre for Policy Studies, 2001: 36).

NAPWA (National association of people with AIDS) in South Africa is a non-discriminatory organization, formed in 1994 seeking to promote a safe and secure involvement that guarantees the basic Human Rights and dignity for those who are HIV positive. This organization strives to provide care and support to the membership as well as to mobilize and organize lobby and advocacy. NAPWA is, moreover, an organization whose membership is open to all people living with HIV/AIDS. Its most important programs are: mobilization, advocacy and lobbying, partnership and collaboration, gender program, organizational development and counseling and support (www.napwa.org.za).

The same structure can be found in Uganda where, because of the seriousness of the situation there, civil society, together with government, labor and business had to be strongly involved in HIV/AIDS related matters. There is an umbrella of people living with HIV/AIDS called TASO, and the 'AIDS services organization'.

The impact of these organizations even though some important achievements is still relatively limited, considering the rapid spread of the disease; Goss and Adam-Smith (1995) argue, however, that pressure groups formed by PLWHA were being represented in organizations and trying to articulate an appropriate response.

One of the most important lessons Africa has learnt in the fight against HIV/AIDS pandemic is that of '*multisectoral approach*⁴', which has proved to be a condition for successful battle. It means that all stakeholders namely government, private sector, the civil society and the media at all levels '*must come together to find ways to work against the common foe*' (Thornton 2003: 23).

HIV/AIDS and Gender Issues

"HIV/AIDS has a female face"

Worldwide in 2004 there were about 37.2 millions adult people living with HIV, of them 17.6 were women and 2.2 children (UNAIDS: 2004).

In Africa the number of women infected with HIV outnumbers infected men. Twelve point two million African women are living with HIV/AIDS as compared with 10.1 million men young African women between 15-19 are four to six times more infected than young men of the same age (Tallis, 2000:26).

Rachel Royce in Vallaers, in her article about *Awareness Is Not Enough: Gender in the HIV/AIDS Pandemic in Africa*, gives considerable ideas on the impact of gender relation and HIV/AIDS. She remarks that HIV has been called a "biologically sexist" virus by scientists, because women are in much greater danger of contracting the disease during sexual intercourse than the man. In the absence of sexually transmitted infections, a man with HIV/AIDS has an average chance of one in 500 of passing the virus to a woman in a single act of unprotected vaginal intercourse. The odds of woman-to-man transmission in the same situation are about one in 1000.

Women under the age of twenty are more likely to contract HIV because an immature genital tract has fewer layers of mucous membrane, increasing the chances that the virus enters the bloodstream. In the presence of lesions in the genital tract, the risk of contracting HIV increases up to sevenfold (Rachel Royce :2005).

⁴ This is the Ugandan approach, developed in the early 1990s.

But Women are not only at a biological disadvantage, but at a social disadvantage as well. World Health Organization (WHO), "Fact Sheet No. 242," June 2000 mentioned that "the second-class status of women in economic, social and civic life has fuelled the pandemic in much of the world." In addition, as Lesley Doyal, a Health Studies expert of Africa, pointed out that "women cannot use condoms in the way most government programs recommend. Instead they must persuade men to do so, and this can be an extremely difficult task." She further argues that in traditional African relations, women are not expected to discuss or make decisions about sexuality. Women do not have control over condom use, they also have little control over their husband's sexual practices. Women are placed at a high risk of contracting the virus, not from their own behavior, but from the behavior of men over whom they have little control.

It looks like women are victims of a patriarchal system that robs them of the freedom over their own bodies.

It is once more clear how women are disadvantaged in protecting themselves.

Following Rachel Royce in Vallaes (2005) in a culture that places such high value on family life, and in which family size is an issue of gaining status and respect in the community, it may very well be futile to urge married couples to use condoms. In this case, not using a condom is in the best interest of the woman as well, because "in many societies, motherhood represents the only route to status, identity and personhood, and ultimately security and support in old age. As one can see, conception cannot be combined with safe sex, and most Africans want large families. Not only is the joy of having children enough reason to disregard the advice of using a condom, but there are other cultural and economic factors as well.

Given that the configuration of gender relation in Africa is associated with sexual behavior and economic security, this relation not only underlies women's particular vulnerability but also inhibit women's security and their families (Beylies: 2000). It is also believed that it is "Only when gender inequality becomes a central part of HIV/AIDS programs can we then hope to make an impact on the course of the epidemic" (Tallis, 2000: 5) So, in addition to biological and social factors, the economic situation of women in Africa also contributes to their increased endangerment of contracting HIV.

The study of rural household in Uganda has revealed that more women are dead than men. The same author remarks, however, that in countries where the majority of infected people are men, women living with HIV/AIDS are often invisible. This means that their needs are not articulated or if they are, they are not heard and not addressed ((Tallis, V., 2000: 61).

In most African countries it is women and men in the midst of their productive and reproductive lives who are most likely to become infected by HIV and die. However, given a typical age difference between partners of five to ten years, females tend to be infected at younger age. Women are infected at an earlier age. Given more rapid disease progression with age, husbands often die more quickly, leaving more widows. (Baylies: 2000:10-12).

Mozambique would not be an exception this gender issue UNAIDS also confirm that the number of women living with HIV/AIDS is growing, and women experience socio economic inequalities and discrimination, particularly aggravated with the deterioration of socio economic conditions in the country given the adoption of market economy, the makes the life waste for women concerning to access health and social services.

www.info.usaid.gov/pop-health.

African men easily forget the fact that performing sexually with many partners place them at risk of HIV/AIDS infection. This in turn has impacts on women who have little power and control in sexual interactions. Such power dynamics in heterosexual relationships raise issues in relation to HIV/AIDS that have been addressed in other

contexts, for example – sexuality, relationships access to health care, women's burden/role in health care and reproductive rights. (Tallis, 2000:60).

This is an indication of how this work cannot achieve more without addressing the issue of gender roles. It is in this regard that the International Community of Women Living With HIV/AIDS (ICW) was created in 1992 at the international AIDS conference in Amsterdam. ICW was created with a purpose to share concerns about the lack of support and dearth of information available to HIV positive women worldwide of Women Living with HIV/AIDS (WLWA) through challenging discrimination and stigma with self empowerment and self-sufficiency, dissemination of information, skill-building training research and advocacy (Artman, 1989: 25).

To return to the importance of our research regarding HIV/AIDS, let us finally remark that in discussing the issue of HIV/AIDS, safe sex and risk reduction, there is a need to take into account the way in which high risk sexual behaviour is embedded in systems of socio-cultural, economic and political exchange, particularly those systems of exchange, which typify gendered power relations between men and women. But all in all, we are enriched through this literature review to understand that HIV/AIDS needs a multiple approach rather than just a single approach

CHAPTER 4 - GENERAL OVERVIEW OF THE THREE PROVINCES IN STUDY

Introduction

The specific nature of AIDS epidemic varies from place to place, depending on historical circumstance, cultural context and contemporary political economy (...) disease is a social event, which expresses the central realities of the society in which it occurs''.(Bujura & Baylie, 2000: 25)

In the absence of a straightforward medical cure, understanding of the spread of HIV/AIDS and advice about how to intervene to limit its spread, should be largely social scientific in nature. Therefore, Social Sciences should provide the main components of the relevant knowledge-base. The very considerable regional differences of social phenomena require a particular mobilization of social science knowledge about each particular society or regional grouping of like societies.

Following this assumption this section focuses on similarities and differences in the three provinces and explains the various factors that may be behind them, in order to trace specific characteristics in the context of HIV/AIDS and its associations. It is important to speak of some economic and social factors related to HIV before speaking about HIV itself in each province. It has been observed, for example, that a high risk of HIV among people, especially adolescent is concentrated among the most socio-economically disadvantaged. There is, for example, a relationship between poverty and HIV/AIDS which includes the spatial and socio-economic distribution of HIV infection in Mozambique. That is why we will discuss HIV in each province by including social factors such as:

- geographical location;

- population mobility; and
- relevant socio cultural aspects that may be behind the HIV community in each province.

These general considerations will be followed by the story of HIV/AIDS associations in each of province.

Talking about HIV/AIDS and its associations which Altman (1994) prefers to call the Community-based organizations (CBOs), it requires first the understanding of what the term ‘community’ is all about because community is at the center of every association.

According to Altman (1994) the term ‘community’ is usually applied to a group of people defined by certain boundaries, such as race, ethnicity, religion or profession. In other words, community is defined in geographical terms; indeed, many of the central works in ‘community studies assume a geographical base to ‘community’. Others have given it a spiritual meaning, as in M.Scott Peck’s assertion that this term should be restricted to a group of individuals who have learned how to communicate honestly with each other, whose relationships go deeper than their masks of composure, and who have developed some significant commitment to ‘rejoice together, mourn together’ and ‘to delight in each other, make others’ conditions our own’ (Altman, 1994:7-8).

In light of the above perception, the author also agree with Peck’s definition of community as a group of individuals who have learned how to communicate honestly with each other and whose relationships go deeper than their masks of composure, and who have developed some significant commitment to ‘rejoice together, mourn together’ and ‘to delight in each other, make others’ conditions our own’. The author also believe that what makes these associations succeed in Mozambique is the fact that people living the same geographical space have the same culture (or belief system) and history to which they add the same sorrow imposed on them by the pandemic. All these things combined can help them to support one another and help them chart the best way forward.

But the question which still persists is what does being a member of a HIV Community mean?

Without a doubt each of these activities represents an important element that makes PLWHAs comprehensive HIV communities. If we go from the predicament that the best thing among people is the one which is the most beneficial for mankind, and that good members of the community are the ones who are productive and dynamic or the ones who care for the welfare of the Community, it is easy to deduce that PLWHAs are part of the HIV community seem to be involved more than the extent to which they personally benefit from the HIV people. They contribute for the benefit of others not looking for a reward. The above arguments give to the word community a broader context which includes both those who live with the virus and the organizations looking after them.

Maputo province

Geographical situation

Mozambique is divided into three geographical regions: south centre and north. Maputo and another two provinces (Gaza and Inhambane) constitute the south regions.

This province has as its board countries South Africa and Swaziland.

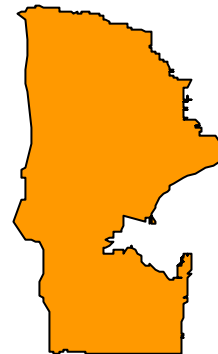


Fig.2 Map of Maputo Province

Population

In terms of population according to INE: 1997 there were 2.700 million inhabitants and the majority was concentrated in Maputo city, with about 1.800 million inhabitants. Maputo has a strong relationship with South Africa through mine labour migration since 19th century. Many people in Mozambique continue to cross the border legally or illegally looking for job in the mine areas or elsewhere like in the farms.

The International Organization of Migration (IOM, 2004) has shown that there is a straight relationship between HIV/AIDS and migration. The HIV infection is frequent in men who work far from home and live in single hostels like miners and others workers. For example there are many mine workers returning home when they are already sick-with AIDS. The risk of infecting others is in sexual relations with their partners while they are infected.

Beside all this, Maputo is part of an important corridor that links this city to Johannesburg, there are so many important roads that link this city to other country in the region such as Swaziland and South Africa from Durban. The same way that the mosquito transmits malaria and the dirty water cholera, HIV is transmitted by contact of people by travelling.

A quick look the city of Maputo clearly shows that in Maputo there is

- a confluence of people from different parts of others province who come to look for jobs or better conditions of lives;
- people from others countries embassies and international agencies are located there;
- there are the most important institutions such as universities, media, trade and enterprises;
- Important sectors of civil society are concentrated here;
- UN agencies and others international organizations, donors and most important meetings and debates about this issue are also held in this city;
- a variety of mass media that help to spread information in the different communities are also found in this city.

These aspects put Maputo in advantageous position over other provinces.

HIV/AIDS ASSOCIATIONS

By HIV/AIDS associations here the author mean the local Aids initiatives which are non-profit organizations dedicated to promoting HIV/AIDS awareness in Mozambique by scaling up nation-wide prevention efforts and improving the lives of persons infected with or affected by HIV/AIDS. Kindlimuka was founded by those who were receiving counselling from AMODEFA. Kindlimuka was created around 1997 in Maputo city. AMODEFA is behind the creation of this association and that is why the members of this association use to say that *AMODEFA* is 'our father'. The first years of its existence the association used the premises of AMODEFA. By that time AMODEFA was working on programs of family planning, giving counsel to couples about issues of reproductive health. The most important part of this association is formed by nurses and other health workers. After some time, it was able to detect people with HIV problems and started to give counselling in this matter also. In 2000 the number of associations increased in Maputo due to the increasing number of infected people who, in turn, contributed to the creation GATVs (Gabinete de Aconselhamento e Testagem Voluntaria) what means Services of Counseling and Voluntary Testing such as *Thinena* and *Kuyakana kudumba*.

In addition, there are many organizations working with people living with HIV/AIDS. Examples of these are *FDC*, *Muleide*, *Kulima*, *Forum Mulher*, *AMME* and many others. These organizations work with or for PLWHA in different parts of Maputo and other provinces providing specific programmes for the Mozambican community. FDC has a specific programme *Kulhuvuka* along Maputo corridor in south region working with widows and giving financial assistance and civic education to infected people while *Muleide Kulima* and *Forum Mulher* AMODEFA are working in partnership with the international institutions and health services in care based home assistance to PLWA..In very recent years *Vidas positivas* 'Positive lives' was created. This NGO's primary aim is to providing counselling to HIV positive people. This organization tries to implement some strategies developed in South Africa. *Soul City Agency* in South Africa supports its actions. *Soul City*, is a South Africa NGO that was established in 1992 to harness the power of mass media and promote health and development in South Africa

and beyond is actually achieving its dreams. Its TV programmes or movies about HIV/AIDS are now implemented in Mozambique to help people know how to handle HIV issues.

Unlike the other provinces, PLWHA associations in Maputo have the possibility to negotiate the implementation of different programs thanks to the direct intervention government departments and other facilities. In short, the dynamic of HIV people associations in Maputo are privileged because the central services of government are based in Maputo as well as the others international institutions including the donors.

Manica province

Geographical situation

Manica province is situated in the central region of Mozambique. This region is composed by three provinces (*Sofala, Tete and Zambezia*). Manica has Zimbabwe as its neighbour.

Population

The population in this province is about 1900.000 of which a major part is concentrated in Chimoio (INE: 1997).

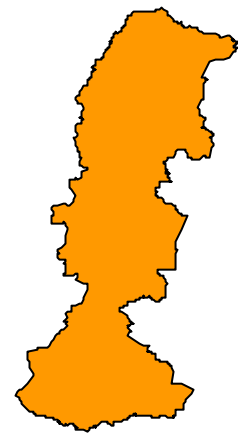


Fig.3 Map of Manica

This province was one of those most damaged by the civil war which lasted for some decades. During this war many people ran away from this province and went to other countries including Zimbabwe as refugees. During that time Zimbabwe was considered as one of the most affected countries by HIV/AIDS in Africa. It is often believed that the return of these immigrants (already infected by HIV in the neighbouring counties) to their own country after war also contributed to the increase or spread of HIV in the province or the country by large.

Besides this war, many socio-economic infrastructures in this country were also destroyed. The local government is still struggling to rebuild these infrastructures. Nevertheless, the recent political and economic crises in Zimbabwe have brought many

white framers from this country to Maputo and who have been exploring the land in this province. That is why Manica is seeing considerable improvement in terms of agriculture and trade these days. The infrastructures such as roads are also developing.

Similarly in Maputo there is in this region an important corridor created in 1990 as a way to strength the linkage between Mozambique and Zimbabwe. The corridor is from Port of Beira (Sofala) to Zimbabwe crossing Chimoio in Manica. This corridor brought large movements of people and goods from each country to another. This corridor, though economically important, has an impact on the dissemination of HIV/AIDS. The districts along this corridor (Beira, Dondo, Nhamatanda, Gondola, Chimoio, Sussundenga and Manica) are seriously affected by AIDS. The highest prevalence of HIV/AIDS in Mozambique is registered in this region with 26%, following by the south region with 19% and 9% in the north region (INE: 2004). The most apparent cause for highest level of HIV/AIDS prevalence in this province is justified by the immigration. Studies conducted by CEP⁵ also confirm that the internal mobility of people a long side this corridor has contributed seriously to the spread HIV/AIDS in Mozambique, in general, and in this region, in particular.

The HIV/AIDS Associations

Rudo kubatana is the first association that was created in this province since 1997. The province was the first one to become aware of the wide spread of this disease as it had noticed many people dying of AIDS by the end of 90s in Manica and more particularly in Chimoio. The return of displaced people from neighbouring countries was the most important reason. *Rudo Kubatana* in the first years of it existence was an important association aggregating many people with HIV/AIDS in Chimoio.

The thing that struck the most the author's mind here is the courage of people in this association in breaking silence about their HIV status (more details in chapter IV). At

⁵ CEP Centro the Estudos da Populacao (centre of population studies) belongs Eduardo Mondlane University

national level actions developed by this association became soon remarkable. Many of its activities gave this association the great reliability. Zimbabwean associations remained the role model of *Rudo Kubatana*. People learned quickly how to organise their association. They learned from what they saw happening in Zimbabwe as this country already had more experience in matters relating to HIV/AIDS as far as the 1980s.

Besides, Guinguirirai was founded in 2000 though its activities already existed since 1999. What is peculiar to Guinguirirai is the fact that emerged out of *Kubatsirane*, an ecumenical religious NGO. Among other activities *Kubatsirane* was working with PLWHA and in 2000 this organization decided to become autonomous. Thus it became autonomous even though it still remains part of *Kubatsirane*. It attends *Kubatsirane*'s meetings and gives advices on a number of issues. They still hold in common some concerns although they blocked out from each other. (Report given by Sister Rosa, coordinator of Guinguirirai, Chimoio: 2004)

GATVs in Manica started in 2001 as well as in many others provinces. In Maputo there is one support group as well as in Chimoio, Manica and Gondola districts. According to the provincial coordinator of Nucleo Provincial do Combate ao HIV/AIDS these three-support groups are preparing to form one association. The dynamic of the PLWHA in Manica complains about the financial resources to develop its activities as Manica people do not have many local donors to support their activities.

Zambezia province

Geographical situation

Zambezia province is part of the central region of the country. It has Quelimane as its capital city.

Population

Zambezia is the second biggest province and the second most populated with about three million of inhabitants (INE: 1997). Like

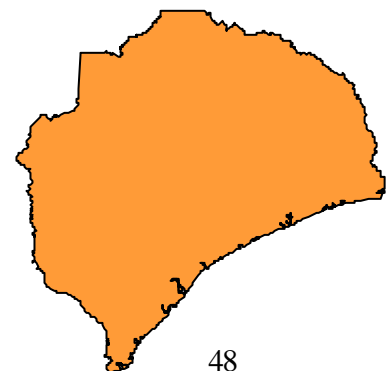


Fig. 4 Map of Zambezia

others capitals Quelimane also absorbs more than 1/3 of the provinces entire population that is estimated to be 1000 people (INE: 1997).

This province has Malawi as the country border. Like Manica province, Zambezia during the civil war saw many people migrating to Malawi as refugees. According to the data, the most refugee people of Mozambique during this war were based in Malawi (PNUD, 1996).

The linkage between Southern and Northern Mozambique is through the Zambezi River. To cross the country through this river is not easy due to the bad state that the bridges and roads in that part of the country. As result, many drivers prefer to make the turn around the river thus taking the route of north region via Malawi. Travelling by air is the fastest means of transport, but it is obvious that this is not given to the ordinary people without enough money. Despite the fact that the government is making efforts to rebuild the bridge, it is a fact that the Zambezia province remains is isolated from rest of the country. Maybe this isolation has for the time being preserved this province from high risk of conducting HIV/AIDS.

The HIV/AIDS associations

PLWHA associations in Zambezia like in Manica are not strong. PLWHA in Quelimane city has two branches: *Associacao Esperanca*, association Hope, and *Kewa*. *Associacao Esperanca* was created in 1997 and *kewa* in 2001. *Associacao Esperanca* has its origins in the provincial hospital. It is reported that this association started as result of blood tests. The increasing number of HIV people in Mozambique pushed the Blood services in this particular hospital to check all the donors of blood. Those found with HIV+ results were advised by nurses to share their burden together. From this mutual encouragement came the idea of starting an association. In 2000 other members of *Associacao Esperanca* decided to create a new branch, *Kewa*. This association is represented by a woman. *Kewa* is dynamic. It tries to extend its activities to other districts or provinces such as Mocuba, *Pebane* and *Maganja da Costa*. In terms of financial support, the PLWHA here get some support from the international NGO such as Action Aid, Save the Children and UNICEF.

“Empowerment” is the most important term to remember from PLWHA. It differs from traditional patriarchal benefactor strategies. PLWHA does not attempt to treat the HIV people as subjects; it emphasizes their participation and maintains the interaction between them, which we encourage here.

Conclusion

To conclude this chapter, the author first remarks that this study of social factors has reinforced our understanding of HIV/AIDS in these three provinces. We need, to remind ourselves that the organizations of PLWHAs need to shift their approach towards HIV. These organizations also have to approach the matter of this pandemic in different perspective. More efforts still need to be put in.

From this brief presentation of HIV overview of these three provinces, the author observed that there are several socio cultural factors that can influence drastically the dynamics of HIV/AIDS association. However two important aspects could be considered. For instance Maputo, the capital, presents more organizations working in HIV/AIDS, as well as, associations of people living with HIV/AIDS, while in Manica the active organizations could be explained by the fact of this province being close to Zimbabwe and learns from this country’s positive experience in this matter.

As a new phenomenon, HIV is a social event. At the same time, it demonstrates many unique features. This means that its impact on community life may be very different from one place to another. This section has shown that HIV/AIDS associations are capable of creating communities that not only facilitate connections between people but also provide supports for their members. Thus, the associations of PLWHA have not only the potential to promote and fight the disease among people in real life but also the capability to construct a virtual community that is part of the real life. The point is, the relationship among people with HIV through PLWHA associations becomes more and more significant. This means the possibility that PLWHA will eventually replace all other forms of associations not composed with people with the virus in the future is evident. This is proven by its new approach which is not only social-oriented but also problem-solving.

The associations of PLWA is formed essentially by poor people has led some to characterize it as a disease of poverty. However, evidence suggests that in some countries the wealthy are also especially susceptible to infection. But in general, it is likely that the poorest sectors of the population are still the most severely affected.

CHAPTER 5 - FINDINGS

This chapter begins with a brief description of the issue of stigma. It gives an overview of HIV/AIDS support groups and how these developed into associations. The comments offered by PLWHA in the support groups and associations are the most important part of this section. The chapter discusses, moreover, questions related to the internal organization of the associations. Also included is a discussion and interpretation of cultural issues obtained from the analysis of People living with this virus. The chapter concludes with a review of the funding in the fight against HIV/AIDS.

Stigma

AIDS-related stigma (or, more simply, *AIDS stigma*) refers to prejudice, discounting, discrediting, and discrimination directed at people perceived to have AIDS or HIV, and the individuals, groups, and communities with which they are associated.

AIDS stigma is expressed around the world in a variety of ways, including:

- ostracism, rejection, and avoidance of people with AIDS (PLWAs)
- discrimination against PLWAs
- compulsory HIV testing without prior consent or protection of confidentiality
- violence against persons who are perceived to have AIDS or to be infected with HIV
- quarantine of persons with HIV.

AIDS stigma is effectively universal, but its form varies from one country to another, and the specific groups targeted for AIDS stigma vary considerably.

Whatever its form, AIDS stigma inflicts suffering on people and interferes with attempts to fight the AIDS epidemic.

Here is a testimony of a man who was diagnosed as HIV positive in Chimoio, 2004:

I never told any body about my situation because I was afraid to be marginalized by them, even my wife I couldn't tell. I only spoke about my condition in the association because I knew that all were suffering from the same problem.

Another testimony quite different from the first one reads as follows:

When the doctor told me that the reason of my long disease was due to AIDS... I informed my husband. Since then, I was no longer at ease at in my house as result my husband decided to take me back to my parents where I am now. My sin was that I revealed the secret...
(Interview with a HIV/AIDS woman in Maputo, 2004).

As one can see, the issue of stigma appears in this second interview. Before, we comment more on the interviews; let us first understand what stigma is all about. Stigma is compounded by fear of an incurable disease, fear of death after long suffering, association of HIV/AIDS with sexuality, and a misunderstanding of its causes. Stigma is indeed deadly because it hinders both prevention of HIV/Aids and provision of quality care. It is also deadly because every human is a social being and when rejected, people become very affected causing death long before the virus could kill. Most of our African countries make the stigma a worse epidemic than AIDS itself (CEA/UEM: 2000).

It is now clear that those who accept their status could live for years, but those who cannot stand the stigma must die earlier than they should. This is very unfortunate because stigma is socially constructed, hence it is curable. An effective way of dealing with stigma is simply assuring people that they are better off knowing their status, that they need not give up if infected, and that there can be quality life after HIV. This is what PLWHA associations are trying to achieve.

These extracts of the interviews demonstrate the level of discriminations related to the HIV positive people, on the one hand, and the importance role played by PLWHA associations where people can talk to one another about their sero status and share experiences.

Origins and motivation for creation of HIV/AIDS groups & associations

The difference between support groups and associations is that the support group is an informal group while the association is a formal group recognized legally by the ministry of justice on one hand, and the existence of structure elected by the assembly on the other. But the objectives, characteristics of the members, the activities are the same.

Some times people of the certain support groups are also members of the associations. It is worth signalling here that most support groups are attached to the hospitals which are their spheres of operation.

The support group origins and function

The establishment of more GATV⁶'s services of HIV-AIDS voluntary counselling and testing help people to check their sero status. These services were created by the CNCS in coordination with the Ministry of Health. The aim of these services to ensure that any one who wants to know about his/her situation does it without any monetary costs. The services are intended to be countrywide provided in order to prevent the spread of HIV through sexual intercourse, maternal-child transmission as well as by blood transfusion. Given this context, the services attempt to reduce the morbidity of HIV- infection through early or prophylactic treatment of HIV infected individual what should include antiretroviral therapy.

According to CNCS, the above services will be provided step by step through the country. They are first guaranteed in the cities where people are the most concentrated. The same source contends that around 2010 these services will cover all health services (CNCS: 2004).

⁶ GATV Is an acronym meaning Gabinete de Aconselhamento e Testagem Voluntaria (Services of Counseling and Voluntary Testing)

Another important aspect related to these services is that wherever they are, they are backed up by **support groups** in order to give an emotional comfort to those people tested positively. As already explained, the integration of people in these support groups is done by GATV services. As soon as people have tested HIV/AIDS positive, they are immediately encouraged to become members of one of these support groups.

There are activists working in these groups whose job is to sensitize people to join the group.

One of the Maputo HIV positive activists went public on her own HIV status and had this to say:

I'm an HIV positive working in this GATV as an activist of this hospital. This job is important because people who receive positive results, if they don't get support of some sort they can even commit suicide. So we stand here as people went through the same experience but alive... and therefore can help others (Interview with an HIV positive activist, Maputo: 2004).

Ivone, coordinator of one of the support group also acknowledges the good results of her work:

I work here as a coordinator of this support group. I used to work for another organization sensitizing people door to door in the community. But when I realised that MSF Luxemburg wants some one for this kind of job, I applied and was accepted. I'm happy doing this because it is a great joy to see that the person who was knocked down by the disease stands up and walks after counselling. It is then that I realised that I am doing a useful job (Ivone, Maputo: 2004).

The drastic growing number of infection in the country and the presence of the support groups can help people to become more and more open and seek for hospitals where they can confirm their status.

It is in this context that Maputo support groups such as Thinhena, Kudunba, Kuyakane and Thinhena youth were found useful to HIV-people. In Manica province there are support groups in Chimoio 'hospital dia', in Manica and Gondola. In Zambezia - Quelimane there is also a support group operating in the 'hospital dia'. Considering the experiences of the already existing associations created from these support groups, it could be assumed that more HIV-associations will emerge in Mozambique. Some of these support groups have contracts with institutions such as Medicos Sem Fronteiras Luxemburg and Switzerland.

One thing that is clear is that none of these messages have led to behavior change. Many of those who were interviewed belong to these support groups and say that they feel secure and happy as members of these groups because they have the opportunity to talk, to share the same situation with others. A woman from Thenema support group confirmed this feeling saying:

When I knew that I'm HIV positive I thought I'm going to die...I really lost the interest in life... but now in this group, I learnt that I'm not alone and I can live longer if I take care of myself (Member of Thinhena, Maputo:2004).

These groups are important because, after a person receives a positive result of HIV feels emotionally down. As a young girl pointed out:

When I knew about my results, I felt abandoned and already dead".
(Member of Kindlimuka, Maputo: 2004).

To elucidate how these support groups operate the author single out *Thinhena*, the group that the author worked intensively with. The author attended many of its meetings and conducted interviews with many of its members. This group was formed in 2000 as a result of the establishment of GATV in health centre of *1 de Maio* in *Polana Canico*. The group is supported by *Medicos Sem Fronteira* Luxemburg.

In *Thinhena* there are more than 90 members that meet regularly weekly following the established calendar:

Monday is the day of general meeting (i.e. for all members of the associations) where they deal with general issues related to their status and the stigmatisation they are victim of in their work places and how to handle that.

Tuesday is the women-meeting day. On this day it is only women of the support group that are allowed to attend this meeting. Ivone Joaquim coordinator of this group says that she understood that women in the general meetings didn't speak comfortably about their problems. This attitude is caused by gender- power relationships already emphasised on. Women are afraid to expose their ideas and tell their experiences because they can suffer some reprisal from their husband at home.

Wednesday is the day of youth meetings. These meeting involve both boys and girls. Specific problems related to their age are discussed. The major concern of this group is to create awareness of how they have to deal with their future despite their status. Issues around marriage and education are also discussed.

On Friday pregnant women attend the (PTV⁷) *Programa de Transmissao Vertical* 'Vertical Transmission Program'. This program of prevent mother-to-child transmission of HIV is supported by USAID in conjunction with the Ministry of Health and others partners. This started in 2002 most in urban areas making a volunteer counselling and testing available for pregnant women as part of antenatal care including greater use of safe delivery services, family planning to reduce mother-to-child transmission, and anti retroviral therapy (Nevirapine) for these positive pregnant women (USAID country profile: HIV/AIDS). Beside all these aspects is also including counselling on appropriate infant feeding.

As women are taught not to breastfeed their little ones and knowing that the level of income for most families in Mozambique is a problem, it was found that such meetings

⁷ An acronym in Portuguese meaning Programa de transmissao vertical what means in English program of vertical transmission. This program is about pregnant women attending the treatment as a way to avoid the transmission of the HIV to the baby.

be done in conjunction with some NGOs such as Santo Egidio and World Food Program in Maputo and Quelimane that supply milk to these babies till six-eighteen months though these programs do not still solve this problem given the fact that babies need milk up to two years. The question is often what will come after six months?

Vigorous controversy exist about whether HIV infected women in developing countries should choose the formula of breastfeeding their infants or not. Breast milk, as we all know, especially in the first months, are vital for the survival of the child because it contains nutrients and antibodies which are needed for the development of the immune system of the baby but have inherent risk of transmitting HIV to the baby. Not breastfeeding babies eliminates HIV transmission but incurs risk of increased mortality whereas breastfeeding has multiple benefits but entails risk of HIV transmission it is estimated by UNICEF that million non –HIV related death per year can be prevented globally through breastfeeding (Coutsoudis, 2002:15).

The other problem is that when infected women are asked why they don't breast feed their babies they have difficulty to explain the reason. Confidentiality is also at risk. Pressure from family especially mothers - in -law force young women to breastfeed thus, increasing the risk to their children to be infected.

From the support groups to the associations

According to the interviews support groups decided to become associations because they felt the necessity to act outside of the hospital and be recognized as groups which have the capacity to talk about situations on behalf of people living with HIV. They started to be organized in way to act outside the hospital, integrating both infected and affected people suffering from the same problem. They were encouraged to establish their own associations.

Then some members start to follow the necessary path to create a formal group with their own vision and specifics aims. Are examples Thinhena and Kubumba in Maputo.

«..we thought to create our own association to explain our situation to whom it concern...and we wanted to be recognized as a organized group

of one's own free will to fight against HIV/AIDS breaking the silence(...) another problem is that the donor institutions only give support to organized groups and recognized by the government...». (Elias president of Thinena , Maputo:2004).

This is confirmed by Elias in Thinena association who says:

We thought to create our own association to explain our situation to whom it concern...and we wanted to be recognized as a organized group with our own free will to fight against HIV/AIDS, breaking the silence(...) Another problem is that the donors (institutions) supported only formal organized groups recognized by the government. (Late Elias president of Thinena association, Maputo: 2004).

Rensida, a national network of PLWHA has been useful by supporting some groups preparing their documentation to become associations. This national network has been supporting also in writing projects and finding donors to support these associations. The most important role of this national network is to co-ordinate the activities of its members, on one hand, and to represent interests of its members in the government and others institutions. It is in this spirit that associations such as Thinena and Kubumba in Maputo were formed.

Overview on the associations

In Mozambique two phases can be distinguished in the creation of HIV associations. However, our purpose is to highlight them and the different metamorphosis they took overtime. The first category could be sent back to 1997-9 when timidly people of HIV/AIDS formed the first associations. In this time these associations were hidden and only people directly related to them knew about their existence. Some NGOs and others institutions were behind the creation of them stimulating PLWHA associations to work with. Later on, these people decided to organize themselves into their own associations. Examples can be given of *Kindlimuka* in Maputo in 1996 and Kubatana in Chimoio in 1998. This word '*Kindlimuka*' means in Tsonga 'wake up'. In other words, it is an invitation to take action as time has gone.

This command fits very well in the context of HIV/AIDS matters where people need to wake up and fight against HIV. Kindlimuka, the first group of its kind in the country, was founded in 1996 and officially recognized in 1998. Today it has more than 330 members, of whom the great majority is HIV-positive. The association strives to reduce the stigmatization of people living with HIV/AIDS by breaking the silence and speaking openly of the illness. It encourages other groups of PLHWAs to seek official status for their associations with the aim of establishing at least one association for each province in the country.

Rudo Kubatana in Manica province is the other association belonging to this phase *Rudo Kubatana* in *Shona* language these words are expressed to encourage HIV positive people to stay together in love ‘people has to be together and in love with each other’⁸.

Associacao Esperanca in Quelimane-Zambezia also means in Portuguese language ‘Hope Association’. This is a challenge to HIV- positive people to think positively and be full of hope for future despite their condition.

The objective of these associations was to give the membership courage and hope. The native names given to theses associations attract local people who deeply understand the meaning behind these names. However, the idea that PLWHA associations can help HIV-positive people is not new, nor is it exclusively African. It does exist in other places as well but seems to be a successful approach in the Mozambican context. The success rests on the fact that most HIV-people feel free to share their burden with their peers who suffer from the same disease.

The second generation of associations of PLWA can be considerate since 2000 until nowadays, in this period observed a “boom” of these associations, the reasons behind this increasing of associations could be associated to the awareness of the government with

⁸ This explanation was given by the president of Kubatana association in Chimoio during the interview in 2004

this pandemic that culminated with the creation of the CNCS⁹ in 2000 a governmental institution with the task to coordinate all actions related to HIV/AIDS countrywide. This measurement shows that the government was committed now more seriously. The HIV/AIDS was assumed as an emergence national matter so including in the priorities of its agenda. (Plano Estrategico Nacional: 2004)

PLWHA as a tool to Breaking the Silence on HIV/AIDS Epidemic in Mozambique

As the fight against HIV/AIDS intensifies in Mozambique, more and more people living with the virus are volunteering to share experiences but we should admit that this is still happening in the confines of these associations or support groups mentioned above.

Janzen in the quest for therapy in lower Zaire found that the people with the same problems, are more confident and the communication becomes more simply when they share the same culture .(Janzen: 1978).

As long as people are ready to talk about it, HIV/AIDS has spread at a fast rate in this country. People living with HIV/AIDS in the associations share their experiences with one another. This indicates that people start now to accept the reality of HIV/AIDS and respond with full understanding of the complexity of the epidemic and the socio-economic challenges it is posing to the nation.

These associations are the best way to deal with HIV as many people make their HIV status known there. The associations also present talks to various groups, help organize HIV/AIDS awareness and education campaigns, and provide HIV/AIDS pre-test and post-test counseling and psychological support to those infected and affected. It is believed by many that people living with HIV/AIDS are potentially the most effective educators, counselors, campaigners and care givers given opportunity and support.

⁹ CNCS Conselho Nacional de Combate ao Sida is an acronym in Portuguese meaning: National Council of Fighting AIDS.

People living the virus are starting now to make HIV/AIDS visible through personal testimony, using sensitive training, prevention campaigns and workplace counseling to bring AIDS into the open and encourage an effective and humane response by governments and civil society.

But their meetings remain the first place where the silence is broken because they are open in speaking about their problems. Those who have lived with disease long enough share their experiences with the new members to encourage them. A senior woman of Thinhena support group declares this, for example:

Times ago people in my district used to point fingers to me saying that she has AIDS. I was ashamed about, but now when I hear some one point to me in that way I confirm my status and I advice him/her to go testing because he can be also in the same situation like me....(Amelia, Maputo:2004).

The whole idea is to give a human face and voice to the epidemic in the minds of people not directly touched by it, "We want to facilitate the acceptance of the presence of HIV/AIDS in the community" (Onen, 1999:2). The more we start talking about the epidemic, the more people will accept it as a reality and refrain from behavior that would put them at risk.

Those in positions of power should strengthen the capacity of communities to discuss the epidemic and the changes they must introduce to survive, and increase effectiveness of national HIV/AIDS policy development programs as the community-based organizations (PLWHA) have started to show the example with its counseling and care activities programs.

Intellectuals should also contribute their knowledge and experience to decision making processes to ensure effective national response to the epidemic. We need to know that we are all at equal risk contracting the virus. Above all the government must make information and tools for prevention and support available to all citizens, increase investment in programs for young people, promote the development and implementation

of policies and legislation that will ensure the epidemic attains priority in the government's budget.

Characteristics of the members the Association

I attempted to gather full data on the characteristics of these members including sex, age, level of education and employment. However, because of different reasons such as the lack of update data base of associations, it was not possible to find these aspects in all associations. Except in two associations *Kindlimuka* and *Associacao Esperanca*, it was possible. The presentation of this data is an attempt to give a picture of what these associations are like. This data is reliable because it is full of inconsistencies.

Characteristics of the associations

Organizations.	Location	T. number	male	female	employment	education
Kindlimuka	Maputo	330	124	206	85 ¹⁰	¹¹
Kubatana	Manica	138	66	72	65 ¹²	
Shinguirirai	Manica	100	40	60	25 ¹³	
Associacao E	Zambezia	350	150	200	22 ¹⁴	50% ¹⁵
S g. kudumba	Maputo	About 50 ¹⁶	32	18		
Thinhenha	Maputo	80	30	50	80% - 15% ¹⁷	

Table 2 characteristics of members of the associations

¹⁰ This number of people employed in this association seems to be high because it includes activists

¹¹ Information about education is not possible to be presented in the table because the data are estimated. For example, the number related to high education is referring to honorary members, while, 35% of the members in these associations never been in the school

¹² Most of them as activist employed through the association

¹³ All employed as activists

¹⁴ 17 of this number are working as activists 8 outside of the associations

¹⁵ 50% are illiterate while the other 50% attended primary school and a few % secondary school

¹⁶ Means that was not possible to get the precise information due to the fact that some member no more attend the meetings of the group

¹⁷ This association estimated the data in % where 80% are unemployed and only 15% employed

Associations must be managed and run primarily by People Living with HIV/AIDS, both affected and infected but mostly the infected ones. They must have or establish a board and officers, as well as an elected finance sub-committee, and a medical advisory team. They must also keep minutes of board meetings and up to date financial records. Associations must demonstrate that they do not discriminate on the basis of gender, religion, ethnicity, sexual preference, and social class; or against sex workers and drug users. The selected members should have demonstrated commitment to their own health by their past and present behavior, such as participation in the association's Positive Living programs.

In short these groups can be represented as this:

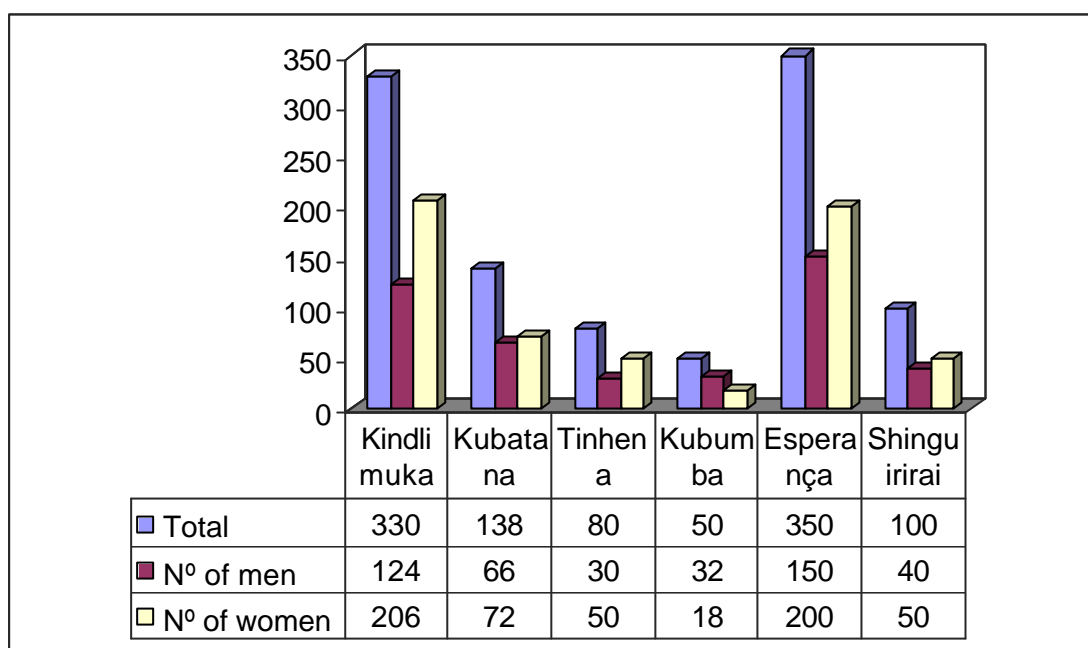


Figure 5. Distribution of Males and Females in the Associations

Gender Issues in the associations

Following the above tables, it is clear that the number of women in all associations is higher than that of men. This is because women find themselves in situations where they need to be tested than men do. They get tested when they are pregnant, they are advised to have an HIV-test and if they are found positive, they are integrated in the associations. Patton confirms this when she says that “many times these women are surprised confront with this situation in conjunction with undergoing some other forms of health care mostly related to their reproductive health” (Patton, 1994:128).

But beside these reasons the number of women increases in the associations because some of them are taken by their sero positive husband advised in the hospital to check their wives’ status. By contrast, women do not have enough power to bring their husbands to the associations. An HIV-positive woman confirmed that when she knew about her situation, the hospital advised her to take her husband for testing. The husband in return responded angrily saying:

get out from my home, I don't want to hear this in my place if you have got AIDS it is your problem don't include me in your affair

As already emphasised in chapter 2, the relationship between women and men in Africa are characterised by asymmetrical power relations, which constitute real barriers to women's social development. Women are always silenced by men in many aspects, especially when it comes to sexual matters.

In fact, if we accept that the most important means to transmit HIV/AIDS is by heterosexual where both men and women can be affected the gender relations are indispensable to be considered. In African society the "women often have too little power within their relationships to insist on condom use, and they have too little power outside of these relationships to abandon partnerships that put them at risk" (Baylies, 2000:6).

Even as Baylie and Bujra think that the best thing to do would be for women to challenge men's power and negotiate for safe sex (Baylies&Bujra, Xii: 2000). But this challenge is not an easy task considering the process of socialization in Africa including cultural practices such as polygamy and rites of passage (initiation rites) that put women more and more in subordination conditions. In these practices women are taught to surrender before the male power if they have to be good house wives.

In almost all African cultures, "women's worth is equated with their child bearing and proofs the men's masculinity (Patton, 1994:140).

To confirm and reinforce this argument it could be important to state the following quote from one of my interviewees:

I'm 29 old and have got three children. The oldest is of my first marriage. He is 14 and another is 9 and the last is this baby here. These two last are of my second marriage. My husband died five years ago. I was always sick and had a skin disease (herpes) and TB as was diagnosed at hospital. I was convinced that I will soon die because I had the same symptoms which my husband had.

Given the persistent of my illness I had to consult the doctor and he advised me to take a HIV test. I did and the results were positive. Finally I was told that I'm HIV positive. At the hospital I was advised by an activist of Kubatana to join his association. So, after the first visit, I decided to be a member of this association. The first day when I get there I recognized many people there because some of them used to come at my home with my late husband as his colleagues. So I realised that every day when he said that he is going to work, he was actually coming to the association. I remember that he never told me where he was working and what kind of job he was doing. My husband was HIV/AIDS positive and he knew it, but never told me about his status. The life at home was natural until he died. Now I have another partner and I got this baby but last year my baby died. We are together in this association....

When asked if she knows that it is not good to have babies because they can die as result of this sickness, she replied:

I know, at hospital they teach us about these things. They say that it is not good for an HIV positive to be pregnant because the body will get weaker and weaker and eventually die. But what will I do? I'm still young and my husband says that he can only pay lobola (bride price) at least if I have a child with him.

In my family no one knows about my situation. It is not easy to tell people about this disease here in Chimoio because you can be discriminated by all people including the family members. Now I'm working here at the association as a cleaner as a way to have some money to support my children.

We speak of African women as being sexually subordinated by men. That topic is also debatable because on the biological point of view, women still have an important role in African society. A proverb from Ghana declares that: A woman is a flower in a

garden; her husband is the fence around it'." (1). That is a beautiful picture of women in African society. The main idea here is to link human life directly with God through the woman. She is created by God, and in turn becomes the instrument of human life. She rightly becomes the one who passes on life. With such a belief, African people both men and women see the bearing of a child is very important than the fear of having one's child infected by HIV/AIDS.

Level of education

The second aspect that comes out from these associations is the level of illiteracy. A country in which 70% of the population resides in poverty and illiteracy the disease (HIV/AIDS) can only be expected to be rampant. This is so because the community has no exposure to programs that can help them and inform them to fight this pandemic and therefore the risk of vulnerability of infection will continue unless alternative measures such as the ones by PLWHA are effectively adopted in the entire country.

There are many reasons for AIDS education. The first of which is to prevent new infections from taking place. People should be given information about HIV, how it can be transmitted, and how people to protect themselves from infection. A second reason that AIDS education is needed is to improve quality of life for HIV positive people HIV+ people should be taught about the importance of not passing on the virus. The third reason people need AIDS education is to reduce stigma and discrimination. In many countries there is a great deal of fear and stigmatization of people who are HIV positive.

This fear is too often accompanied by ignorance, resentment and ultimately, anger. Sometimes the results of prejudice and fear can be extreme, with HIV positive people being burned to death in India. Discrimination against positive people can help the AIDS epidemic to spread - if people are fearful of being tested for HIV, and then they are more likely to pass the infection to someone else without knowing (HIV&AIDS Education, 2005)

It is a fact that the people who are most urgently in need of HIV education and in these associations are poor or ordinary people. Those educated people who hold high positions in the government or local authorities though HIV+ are completely absent in these

associations. They get their assistance or treatment from private clinics or outside the country. This is so because of the fear of discrimination in Mozambique.

Unlike these educated people, the uneducated ones feel free to talk about their sero-status. They appear on TV programs confessing publicly being their sero status. TVM program “Vidas positivas” makes efforts to bring middle class people to do the same but they timidly respond to this program’s invitation. Maybe the reason why the poor people easily break the silence is because they have not much to lose and in so doing they know they will maybe get some money or others forms of compensation to face the starvation problem.

This was confirmed by two young boys in Chimoio who told that when they broke the silence by declaring their HIV status they used to receive some incentives.

“... when we gave this kind of information about our HIV status we used to ask for some incentive... and coming out in the open is not easy... many organizations used to give us some money...” young boy from Guinguirirai Association, Chimoio: 20004).

From a handful of courageous individuals who went public about their HIV status in 1999 in the capital, Maputo, there is now a nationwide network of 28 associations of people living with HIV and AIDS (PLWAs) (Rensida: 2004). Yet stigma and discrimination persist.

Considering the level of education and employment, one can conclude that these associations are weak. On one hand, it is not easy to do voluntary work and the same time try to feed the family since the majority are unemployed and on the other hand, because the members are illiterate, they can not make well-informed decisions in the running of the associations.

The general picture of Mozambique is that is a poor country ravaged by AIDS with a high employment and low education level. Despite this picture, there are some rich people in good positions in the government and civil society. Although these may suffer from AIDS, usually they do not belong any of these associations.

This kind of attitude is not good when you want to break the silence. Mozambique is still not doing well in breaking down the culture of silence among influential people. The experience of Uganda shows that when influential people come out in the open and announced their HIV/AIDS status, more people were influenced to do the same. It also led to an increase in sensitization of the general public on issues that relate to HIV/AIDS.

Organizations like TASO and individuals like Pilly Lutaya in Uganda “ put a human face to HIV/AIDS” . Ordinary people were able to associate AIDS with rich people, and joined hands together in fight against HIV/AIDS. (<http://www.aidsuganda.org/pdf/role-ofvct.pdf>).

Unlike Mozambique in many countries such as South Africa we hear stories from people who live or have in some way been affected by HIV/AIDS. They reveal their status honorably. However, for the vast majority of people living in these counties, human rights are respected and people have learned to live with HIV+ people with dignity. This is a good example to follow for Mozambique where everyone needs to learn how and why not to discriminate against positive people.

Altman comparison of HIV organizations in Africa with those in USA found that in the USA these organizations are far stronger and organized in terms of political representation and advocacy than they are in Africa or other developing countries (Altman: 1994: 58-59). In our understanding what makes them this way can be attributed to wealth, fight against discrimination and high level of education of those working in these organizations.

Employment and HIV care

HIV-People in Mozambique, estimated at 13% of the total population within a country continue to face difficult lives without access to any basic services.

Education, Transport, Health and Employment services do not exist or are very scarce and do not satisfy the needs of this social group. The mass media do not give attention to the specific needs of people.

Mozambican society in general, continues to look at people with disability including HIV- people as useless and incapable; subjects them to constant marginalization and discrimination; and gives them no space to participate in the massive effort of recovery and development of the country.

It is important to observe (see tables 1-7) that most members of the associations are unemployed. In this item we used two categories of employed people: one referring the people employed outside the association in public, private or informal sector, and the other referring to people considered employed by the associations working as activists in the GATVs or hospitals. Since they receive their minimal incentive, they consider themselves as employed people.

This incentive correspond about 500000\$00mts equivalents about R 150\$00 per month. This amount is insignificant if it has to cover the needs of a household with at least 5 to 6 people. In INE and PNUD report, Mozambique is considered as one of the poorest countries in the world where people are living with less than one UDS dollar per day. The actual minimum salary in Mozambique is 1.200.000mts meanwhile the basic needed for a household of 5 people are calculated in double of minimum salary in 3.300.000mts (OTM Cental Sindicato: 2003)

Given the low possibilities of employment most people in these associations are concerned in having this kind of job as an activist and they consider themselves as employed despite this low income.

For example in Maputo the coordinator of the Kudumba support group, said that when the association was formed most of members got employed as cleaners or gardeners at the hospital where the association is based. That attracted other people to join the group so that they could benefit from the incentives. It, was not possible to employ all or the people because the jobs were limited (coordinator of Kudumba, Maputo: 2004).

It is in this regard that the board of the association came to the understanding of the fact that people working in the association with children to look after qualify (should obtain)

for such support grant for survival. The president of association Kewa in Quelimane argues:

One of the most important objective of the association is to ensure that the members have the minimal for survive... many of us are not working because we lost the job due to the illness... so we have to do something for them in that way (Ana of kewa association, Quelimane:2004).

In this way, we see the PLWHA as having gone one step further from their emphasis on HIV/AIDS education to care. Education was (is) important, but now that the pandemic is full-blown, the need for care had become more urgent.

In South Africa a disability grant of R740 per month (US \$108) is available to people with CD4 cell counts below 200. It is believed that HIV-people who cannot work find themselves in the category of those with disability and are eligible to such grant.

Unfortunately, there are some misconceptions among the young girls who sleep around with men without condom. They do not mind contracting HIV so that she could access the disability grant. Here also the South African government (the department of social development) has the duty determine how to improve the grant system and prevent such perverse incentives.

Caregivers need to receive a salary, which can help them and their families to survive. We do, however, agree with the fact these people have been trained in basic nursing skills, but are not health educators or full nurses as such. But it is also true that they cannot work for nothing.

In short, a number of issues impinge on the PLWHA's contribution to HIV/AIDS. High illiteracy rates, unemployment, underemployment, lack of scientific awareness of HIV/AIDS epidemic, a high population growth rate and cultural misconceptions, are some of such issues affecting the policy that PLWHA proposes to address.

Description of the association's offices

This section describes PLWHA addressing HIV/AIDS in Mozambique that were visited during my research in Maputo and other provinces. The offices outlook, the associations' functions and chart will be presented as well.

To start with, most of the offices of the associations are small houses in annex of the main house (dependencia) and in degradation situation (i.e. without renewal painting, electricity and water) with the exception of kindlimuka in Maputo and kubatana in Chimoio whose offices are independent properties.



Figure 6 This is the office of *Kindlimuka* association with the logotype in the main entrance

But both of them faced some problems related to the payment of the rents. Kindlimuka , for example, moved twice from one office to another in 2004. Kubatana was in search of a less expensive and affordable office as their donor notified them that he will stop paying the rent simply because the association mission in the province was nearly to finish.

Others associations work together with NGOs or other institutions as they are unable to afford the rent. This is the case of Guinguirirai in Chimoio working at Kubatsirane office. Kuyakana in Maputo is also working in the premises of the Rensida office while

Associacao Esperanca is with MONASO in Quelimane. And finally Kewa in Quelimane is given a small room in the provincial hospital.

It is also important to emphasise on the fact that these offices are located in hidden places. Is not easy to find them unless one is taken by hand to these places as they do not even have the advertise signals pointing to where they are located.



Figure 7 the road to get the *Thinhena* association some where in the district of Laulane close to Maputo city



Figure 8 The *Thinhena*'s office association

Mozambique faces many challenges. Even though PLWHA continues to play a paramount role in educating people about HIV/AIDS and sharing of experiences with the government, the political parties about this pandemic.

Structure and function of these associations

The way in which HIV people associations are structured is based on the one adopted by the most of NGOs in Mozambique. To be legally recognized an association in Mozambique an organization has to be recognized by the ministry of justice. Ten members at least have to sign the status in representation of the others members. Others requirements are: the *estatutos*, describing the aims of the associations, general presentation about the members, the structure of function of the different organs.

The basic organization chart looks like this:

The structure of the organisation: Principal organs and the function

Organization Chart

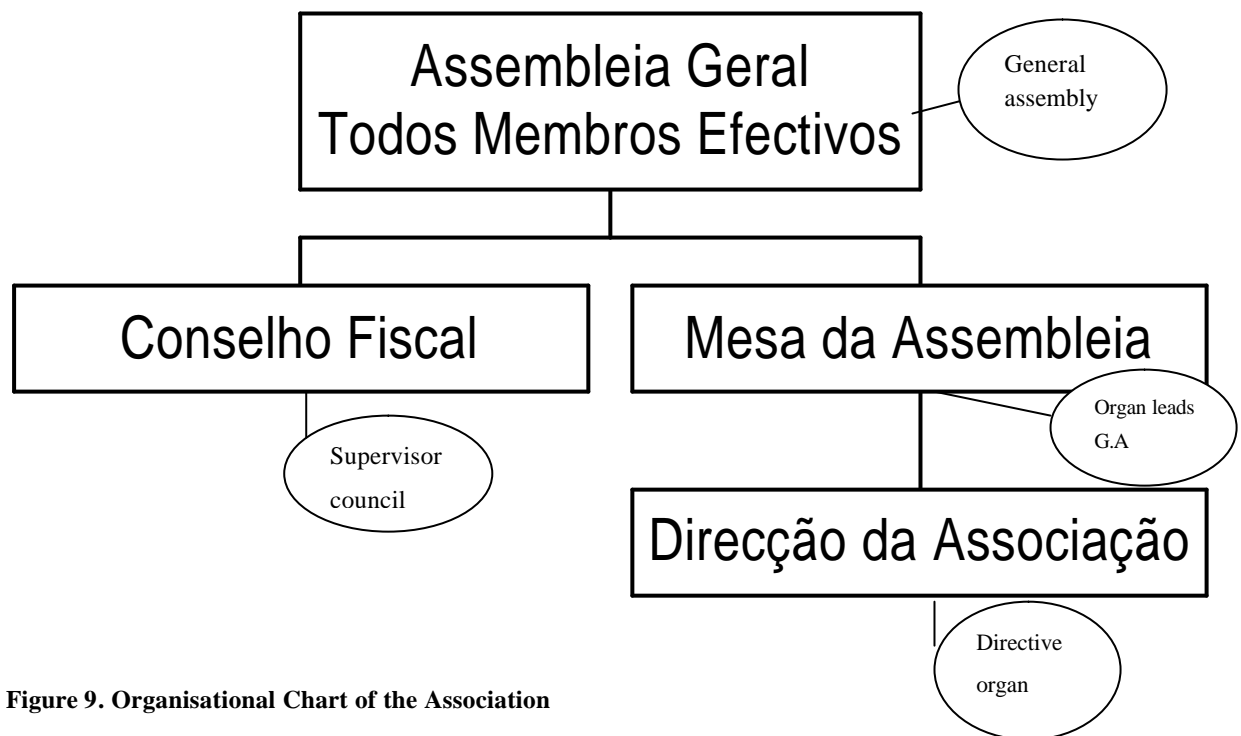


Figure 9. Organisational Chart of the Association

Sources: This organization chat was based on different status of the association (Thinhená, kindlimuka, Muleide, AMMe, kubatana).

Function of the associations

According to this chart the principal organ is the **General Assembly**, a president supported by one vice president and one secretary composes the presidium of this assembly. This is the main organ because it is where all aspects regarding the life of the association are being discussed. The alterations of the status, admission of new members, examination and approval of annual activities reports as well as financial reports are also part of this organ's agenda. The ordinary meetings occur once a year while the extraordinary can occur anytime when required by the direction or by 1/3 of its members.

Below the general assembly comes a **Directive Organ**. This one is composed by a president, one or two vice presidents and the executive secretary. This organ is the executive structure that deals with the daily activities of the association. The directive organ represents also the interests of the members. It is, in addition, responsible of the mission and vision of the association in the country and outside.

The **Executive Secretary** is not elected in the general assembly; he/she has to apply for this position according to the requirements set up by the association. The secretary spends her/his days coordinating meetings, making travel arrangements, and managing schedules. In between, she answers telephones, emails, and faxes. His/her major function of the Executive Secretary is the coordination of activities from the association's members, donors, and the international organizations.

The other important organ is the **Supervisor Council**. It is also composed by three members who are: the president of the council and two vocals members. This is also an important organ because it supervises all the activities of the association.

Normally these organs have the duration of three/ four years. Candidates of different organs have to observe three conditions: (a) to be effective members, (b) to be a HIV+ and (c) have leadership qualities.

As far as the schedule of other organs is concerned, their members have specific meetings weekly. They also have sometimes meetings with the directive members to analyse different activities.

As regards **the membership** of the association, we distinguish three general types, which are:

- The effective members,
- The honorable members and
- Sympathetic members.

The effective members are all HIV+ people who identify agree with the aims and objectives of the association. They are the key members not only in terms of numbers but mostly because they are the real cause of the existence of the association. Most of them are recruited through the activists working at the GATVs services. These activists start by presenting their associations and explaining the advantages of being member based on their own experience. It is in this way that they have been able to convince and attract as many people as possible. The process of becoming a member usually follows the same pattern. One member explains this process as follows:

[...] In 1999 continuously suffered from malaria and headache. I was also losing weight considerably. The medicine I was taking didn't solve the problem, so the doctor advised me to take a HIV test... the result was positive. Before the test I was asked by an activist of Kindlimuka to be a member of this association, and I joined.

Another member in Manica explained how he became a member of Guiguirirai in this way:

I took an HIV/AIDS test because I was always sick. I was told by some activist of this association about the advantages of being in this association. So I decided to visit the association and later I became a member...

Most people become members of the association after being referred to them by activists in the hospitals and GATVs. Stories such as these are numerous. Two aspects came out: the first one is that people normally go for a HIV/AIDS test when they got a persistent disease. The other aspect is that people become members of the associations because of the job of the activists at the hospitals inviting HIV positive people to join these associations.



Figure 10. Members of Kindlimuka association in the office.

Honorable members are people with influential positions in the society. These are, for instance, the members of the government or the civil society. In the Kindlimuka association we have members such as the prime minister, the minister of health of Mozambique, and the national head of HIV programs in the health ministry. There are also members of international agencies who contribute financially for the advancement of the association.

We have finally the **sympathetic members**. This category includes people working in the field of HIV from different sectors of the society as well as people working in the health services. It also includes anyone interested in HIV matters.

Rights and obligations of members

To be involved in the activities of the association gives one the freedom of speech in issues related to the association. Any member is in the obligation of paying a symbolic amount of 1000.00mts (i.e. some cents if converted in South African rands) as a symbolic contribution to the association.

Being a member of an association is very beneficial. One of most important benefits could be to access automatically the ARV treatment but is not what is happening. The government has a policy on the provision of antiretroviral treatment (TARV) that

involves these associations. The section of the Anti-Retroviral Treatment in Mozambique (Section 4.4.3.1) below expands more on the benefits of being member of the association and the role of this treatment.

The association and the Anti-Retroviral Treatment

As part of their rights members of these associations stand the chance of benefiting an efficient HIV treatment.

In theory, there are 3 strategies to contain the HIV/AIDS epidemic:

- To vaccinate everyone against HIV;
- To change sexual behavior;
- To provide anti-retroviral therapy (Gorik Ooms, 2004).

Of these three, the two first will take time before the change occurs. The countries, who favored the prevention via change of sexual behavior such as Uganda, now start to upscale anti-retroviral treatment. Effective anti-retroviral treatment seems to be the best option today but it requires patients to know their HIV positive status in an early stage of the syndrome.

Kindlimuka and GASD were among those associations that tried to address this issue of anti retroviral treatment in their programs. But according to the rules of the country the anti retroviral treatment (TARV¹⁸) is administered following the principles below:

To be eligible for this treatment one must fulfil the following:

- The confirmation of HIV/AIDS positive test by any national service of health.
- The level of CD4¹⁹ cells must be tested below 200 (point which indicates AIDS).

¹⁸ TARV is an acronym in Portuguese meaning Tratamento Ante Retroviral translated to English could be Anti Retroviral Treatment .

- Have at least one individual around who can assist in administering this treatment.

It should be noted, however, that this treatment is provided to all those who are infected by HIV independently if is or not a member of any association. This program is in the responsibility of the Ministry of Health. The ministry has a national program for this kind of treatment. There exists a specific program that is at the disposal of the members of HIV /AIDS people that belong to the associations. In other words, this treatment does not privilege any one but every body has right to it.

According to this ministry the TARV already started in Mozambique in 2000. Each hospital receives for the TARV program at least 75 new cases per month. In all provinces the workers of this program confirmed that people are really adhering. In Chimoio, for instance, the Dia hospital receives more than 75 new cases per month because this Hospital has been receiving also patients from different districts of this province. (Interview with the director of health, Chimoio: 2004).

According to some patients the effects of this treatment are visible and the treatment is therefore seen as effective. One of the patients at Maio Hospital acknowledges:

[...] when I started this treatment, I was too slim I couldn't even work, my mum had to carry me like a baby...but now, as you can see, I'm now putting on some weights ... people don't believe that I am sick (A patient of I de Maio hospital and member of support group, Maputo:2004).

However, to be administrated such a treatment, it is important to be aware of its side effects. Therefore one needs to feed on a solid and nutritious diet. But as many people live under poverty in this country, we believe that starvation could be also the major reason for deaths. On the other hand, interrupting such a treatment does not help the patient at all, it does, instead, create the virus' resistance to the medication.

¹⁹ CD4 or (t cell) lymphocytes are a group of white blood cell that normally help guard the body against attacks by bacteria, virus and other germs. When CD4 has decrease progressively to 200 cells or below the person has developed AIDS (<http://www.intelihealth.com/IH/ihlih/ws/h www/>)

Anyway, Muleide, an activist working in some suburban area in Maputo one said that people in general are reacting well to the TARV programs. Another aspect to it is that, the experience of care home-based care services are applied in so many developing countries because the health services cannot afford to deliver their services to a huge number of infected people. As a new experience there are some difficulties in dealing with them. That is why it is accepted that HIV associations deal also with such cases though requiring a little bit of expertise that most activists do not have.

The important is that the ART is shown efficient to minimize the AIDS. People who already started this treatment have given good reports. The Mozambican government is lobbies also to have more money in order to subsidize these drugs for more HIV positive people. The actual cost of ART treatment in Mozambique is about \$ USD 250 year per person. Is too expensive for a poor country like Mozambique, that's why the CNCS National council of fighting HIV/AIDS assumes that the first strategy should be the prevention. (Plano Estrategico Nacional: 2004).

Activities & responses of members belonging to the associations

Much of the counseling, education and peer education work which is carried out with HIV positive people is conducted by HIV positive people. Many projects are shaped by HIV positive people themselves, given the insight they have into what it is like to live with HIV / AIDS. A good example of such a service - run by HIV positive people for HIV positive people - is *Kewa Association* in *Quelimane* where one of the members stresses the unity among members in the following terms:

*Here we are like brothers and sisters. We use to come here to talk each other because at home we don't have the same comfort we have here
(Member of Kewa association, Quelimane: 2004).*

The other membership expressed also his feeling in these terms:

I can't lie to you. I'm feeling much better here than at my own home. Here I got friends with whom I can joke and talk bout any thing... So, I come

every day here and spend my day joyfully (Kewa association, Quelimane: 2004).

In short, these associations in all the three provinces are developing the same activities:

- Mutual support in the association through home visits.
- Educating people at the market places, in schools, workplace by making use of themselves as examples of HIV positive people.
- Giving counselling at the services such as GATV and hospitals.

The activists of these associations receive themselves a special training from national organizations such as AMODEFA and MONASO working in conjunction with the ministry of health. The activist's visits not only are important for the patients suffering with AIDS but also by enriching contact with the family members and advice about the illness. In so doing they help those who are not sick to know how to support the family members who are infected by AIDS. They become aware of how the disease is being transmitted and reduce the fear they might have by increase their compassion and cooperation for the patients.

It is worth repeating that civic education plays an important role in sensitising people about HIV/AIDS, especially when it's being conducted by an HIV/AIDS infected person. The message has greater impact on the audience because the messengers talk about their own experiences as people who live with the disease.

The home-based care and treatment is very important in many respects. Firstly, it enlightens the family members who are ignorant about how HIV transmitted. Secondly it helps in teaching family members to be compassion to HIV/AIDS patient because the activities are compassionate. It can be agued that the home based care treatment in Mozambique is supplemented by grassroots organizations. So, it is believed that this treatment can become more and more effective and sustainable if grassroots organizations are linked to existing public health services. However, this linkage is not effective because the public health care services are inadequate and insufficient.

The other activity undertaken by these associations in order to sustain them is income generating activities. These include the following:

- Embroidering and weaving different materials for sale
- Selling traditional medicine which is extracted from African potato
- Subsistence agricultural activities

In brief, this grassroots' action and other activities have an impact on PLWHAs by providing secondary income to sustain them.



Figure 11. These members of Kindlimuka Associations sewing staff of selling



Figure 12. *Some member of Thinhena association making vases for selling also*



Figure 13. This picture also is showing a group of women swing

Family: An important source of support for HIV-positive People

People diagnosed with HIV often turn to friends for support, and that's encouraged by doctors and therapists. But Ohio State University research suggests this advice may not go far enough. In Serovich's most recent study, published in the journal *AIDS CARE*, she found that the 134 HIV-positive men were less likely to be depressed if they received support from their families. In another study of 142 HIV-positive men, published in *AIDS Education and Prevention*, she found that subjects who received social support from their families were less likely to engage in risky sexual behaviors than were men who did not get social support from their families.

Serovich does not say that all HIV-positive people should tell family members, nor does she believe all family will be supportive. Some may, in fact, be hateful. So, HIV-positive men should consider seeking guidance from therapists or other helping professionals in making decisions about disclosure to family. And therapists need to encourage exploring those options.

People often need help in figuring out how to disclose their HIV-positive status to anyone, and it's important that they do so. It has been observed that people who disclose their status are more likely to get necessary medical help and find out about clinical trials, new therapies, family support or other options available to them than those who do not disclose their status.

In most cases HIV family members in Mozambique have problems supporting their family members who are sick. This is partly due to lack of knowledge of how to deal with the sick, on the one hand, and to lack of disclosure of those who are sick to their family members, on the other. In fact, many of these HIV positive people argue that it is difficult to inform the family members about their status as well as involving them in the association except in cases where the husband was tested positively and the GATV advises him to bring the partner and this one is also tested positive. But generally speaking families are not involved as pointed out by a member of Esperanca association who once said that

My family doesn't know that I belong to this association. In fact, I never told them ...not even my wife. Because I don't know how they will react (A member of Esperanca association in Quelimane: 2004).

In Chimoio a member corroborates this idea when she says that

I didn't know anything about this disease until my husband who was always sick and had skin problems for years asked me to go with him to the hospital one day. There I was tested HIV positive. He finally revealed to me that he was he also HIV+. This is how we are together in this association (An HIV positive woman in Chimoio: 2004).

This shows how women rarely learn about their husbands' status.

In cases where the woman goes first to the hospital and asks her husband to attend the consultation at hospital this one often responds in these words

You, go if you think you are sick, I'm fine (A member of Thinena support group, Maputo: 2004)

It is clear that the power of the man surpasses that of the woman in Mozambican patriarchal society as such man has a power to influence his wife to go to the hospital and not vice versa.

The anti-retroviral treatment referred to in section (4.4.3.1) requires that family gives support to HIV patients. In fact, when people start the TARV treatment the health service worker obliged them to tell members of their families because of this treatment once started it cannot be interrupted, and these drugs can bring out collaterals symptoms that it becomes therefore important that the family member encourages the patient to go further with it. The counsellors in Maputo association are aware of that as one of them remarks

When people have to start the TARV treatment we require that they come with at least one family member to will be looking after the patient at home. This person needs to be informed about the TARV treatment and its

effects in order to assist the patient whenever he needs help (Officer of MSF, Maputo: 2004).

It is wrong to assume that family support is mostly needed when the patient goes through the anti-retroviral treatment. This support is needed even for orphans (victims left behind by HIV/AIDS deceased parents).

Support for orphans by family network

While we praise Mozambique for its initiative to create its first hospital for HIV-positive children officially opened in Maputo on 24 May 2004 as the country was struggling to cope with more than 30,000 children born each year with the virus that leads to AIDS, we encourage the country to make however a further step. In fact, one of the most devastating aspects of the HIV/AIDS epidemic today is also the growing proportion of children the disease has orphaned. Unlike most diseases, HIV/AIDS generally kills not just one, but both parents. What is more, the stigmatisation and discrimination that people affected with HIV often live with is passed onto their children, making their fight for survival much more precarious.

When parents or caregivers fall sick and die, a child's life often falls apart. With HIV and AIDS, the hardship hits well before children are orphaned. First a parent or caregiver becomes ill with HIV or AIDS, and is unable to work. The entire family feels the economic impact – children, especially girls, must often drop out of school to go to work, care for their parents, look after their siblings and put food on the table. The situation becomes worse, as already said, when both parents die.

If there is one dimension that PLWHA needs to look at very attentively is to develop a system where children can be protected in their environment by the extended families. We believe that African traditional solidarity is naturally a framework that can be exploited and encouraged by governments to take care of children who had lost their caregivers. In this regards, UNICEF believes that whenever possible, children who are orphaned should remain in their communities to be raised by their extended family. Recognizing that family care is far better for children and far less costly than institutionalized care, children who grow up in families also develop better social skills

and are psychologically better adjusted than those who grow up in institutions because they receive more affection and attention and develop a better sense of personal identity (www.unicef.org/aids/index_orphans.html). We totally agree with such an approach, which we believe should be given thought in Mozambique as well by PLWHA.

PLWHA Organizations and fund opportunities

PLWHA & Other Organisations

As already mentioned in chapter 1, the National Response to HIV/AIDS in Mozambique is positive. It passed through several stages. The National Control Programme against STD/AIDS (NACP) was created in 1988, and the first Medium Term Plan (MPT1) was developed. The NACP has a central body, located in the Ministry of Health, and regional offices in 11 provinces. The main responsibilities of the NACP include planning, coordinating, monitoring, and assessing provincial plans, and providing technical assistance to government sectors involved in the program. The NACP also develops short- and medium-term plans and establishes cooperation protocols for Mozambican and international NGOs, donors, and social, religious, and mass media associations. A second Medium Term Plan (MPTII) was developed in 1994. The National Strategy to combat STI/AIDS includes prevention, counselling, epidemiological surveillance, and blood testing. Specific components of the national program include management, information, education and communication (IEC), epidemiological surveillance, laboratory support, care of PLWHAs and counselling, and condom social marketing (Plano Estrategico Nacional).

Organizations in Mozambique such as (MONASO) brought together a variety of organizations working on HIV/AIDS activities throughout the country. MONASO's credit is to have prepared an organizational strategic plan to provide more effective coordination and assistance to local NGOs. With increased disclosure of HIV-positive status, a network of PLWHA has also been formed, and partnerships have been created between the network, other NGOs, and the government

Donors/Funding

Though PLWHA organizations are involved in counseling and psychosocial support, home-based care, training of members, education and awareness activities, these organizations still face various management problems including inadequate technical skills to run their organizations and difficulties in raising funds.

PLWHA in Mozambique have had access to financial supports over years that strengthen and support an expanded response aimed at preventing transmission of HIV, providing care and support, reducing the vulnerability of individuals and communities to HIV/AIDS. But most of the members of PLWHA associations when interviewed refer to finances as the major problem that causes troubles within the associations themselves and their relationships with other institutions. If we consider Elias argument when he says that

We got good relationships with the foreign NGOs; they give us money to develop our activities. The problem is that we don't get that money on time even after the contracts are signed. (Elias at Thinena association, Maputo: 2004).

Such a quote shows that not only these PLWHA associations had nowhere to turn to for assistance, but the PLWHA organizations are faced with organizational problems as well because many members do not have the necessary skills to run the organizations. They need to develop advocacy, fundraising and communication strategies to overcome these problems.

But before we go into all that, let us first remark that multilateral and bilateral donors are actively engaged in Mozambique. **UNAIDS** has a coordinating theme group based in Mozambique since the 1990s. The group, chaired by WHO, consists of representatives from UNDP, UNFPA, UNESCO, The World Bank, WHO, and UNICEF. In addition, major bilateral donors who provide the bulk of AIDS financing in Mozambique are active leaders of the group.

The World Bank supports HIV prevention as part of a road construction project. WHO is carrying out joint activities in the areas of epidemiological surveillance, STI and HIV/AIDS counselling, prevention interventions for vulnerable groups, and blood safety. WHO also provides some direct support to NGOs. UNDP is implementing a comprehensive national AIDS project. UNFPA will support improved integration of STI and HIV/AIDS services into existing reproductive health services in its country program from 1998 to the year 2000. Finland's Ministry for Foreign Affairs, Department of International Development Cooperation, supported a \$1.1 million community development project from 1995 to 1997. The project, implemented by The Red Cross of Mozambique, provided information about HIV/AIDS, nutrition, maternal health care, and hygiene, as well as blood transfusion services.

Pepfar (President's Emergency Plan for AIDS Relief), Mozambican government is now one of the recipients of US President George W Bush's \$15bn Emergency Plan for Aids Relief (Pepfar). But the beneficiaries of Pepfar cash are only allowed to buy drugs approved by the US Food and Drug Administration (FDA). This effectively rules out the vastly cheaper generic treatments that Ms Muhai benefited from. Orla Ryan (2004), BBC News business reporter in Mozambique says that Pepfar represents a healthy injection of cash into the fight against HIV/Aids. Just as importantly, it is the result of US recognition that action is urgently needed.

Private Voluntary Organizations (PVOs) and Nongovernmental Organizations (NGOs)

A number of PVOs implement activities in Mozambique, funded by multilateral and bilateral donors. Some of the major USAID cooperating agencies include The Futures Group, and Population Services International. According to UNAIDS, a relatively small number of NGOs are working on HIV/AIDS prevention and they are concentrated primarily in Maputo and other urban areas. The majority of NGOs receive their funding from external sources and work at a micro level, with limited impact on the epidemic at the national level.

These NGOs, however, do not assist financially unless the associations fulfill certain requirements. This is maybe what the adviser of Rensida (National Network of PLWHA associations) meant when he said that foreign NGOs and donor institutions are tough when it comes to financial support. They give money only when the project submitted to them fits their requirements. Sometimes this is not easy as the organisations have to adjust the project in such a way that it suits them in order to get money. So this kind of relationship is that of dependence. The organisation totally depends on those who have money to function.

This shows that the associations do not have a good dialogue with donors. The organisations have at all cost to accept their conditions simply because they have resources which we do not have. This situation has turned many people to deal with HIV issues depending on how able they are to plan or write a project and not out of real passion for HIV people. People in desperate need of income would go for project NGOs require in order to get finances (Motlhaolwa: 2001: 27-28).

Caution should be taken, however, not to generalize this situation because our research reveals that some international donor agencies are flexible and are willing to discuss and altering the implementation of projects presented by PLWA associations even if it does not fit their agendas.

Accountability is another problem that arises when dealing with financial support issues. In fact, most of these international NGOs demand the associations to give account of how the money given has been used. MONASO and RENSIDA are aware of this problem. Most PLWHA associations struggle with that problem. But it should be admitted that with good managerial skills, integrity, honesty and transparency this is not a big issue. There should be no fear of being accountable to somebody.

On the other hand members of the board of these associations manifest their disappointment in that even though they are given some money by their donors this money does not respond to the needs of the associations with its multitude of activities.

In response to this international NGO's and others institutions argue saying that PLWHA associations are not able to deal with big amounts of money due to the weakness that their administration presents. An officer points out

If they even have problem in justifying that small amount how can we trust them giving more money? (Officer of Action aid, Quelimane: 2004).

The officers are also reluctant as they believe that pumping in a lot of money for HIV/AIDS will not help as the money would be used for other purposes other than fighting against the pandemic. This is confirmed by Ivone who argues:

I don't think that all this money in Mozambique in name of HIV/AIDS is effectively used for the suffering people... there are so many organizations working in on this issue but why is it that the number of infected people increases daily? (Ivone , Maputo:2004).

In Chimoio a NPCS officer adds also that

Something has to be done in order to know really if what all these organizations say is true ... I started to organize the map with all details of each national and international organizations to find out what, where and how they operate in the field (Officer of NPCS, Chimoio: 2004).

As for the president of Thinena association in Maputo

The number of seminars and workshops run in this country and in the world if enough and if the money spent on HIV/AIDS was spent to a productive goal by then this disease could have been already minimized... (President of Thinena association, Maputo: 2004).

For him but the results in the fight against HIV in Mozambique are not satisfactory. According to the Strategic National plan with its new executive secretary it is important that the plan be shifted into another direction. He thinks that in the next few years to pay more attention to the suffering people mainly the orphans. It is in this regard that the CNSC has given more assistance to the orphan programs in the country nowadays.

Still on the front of funds for HIV/AIDS, others complain that they do not benefit from the few that come in for HIV/AIDS programs. The president of Thinena association in Maputo sadly remarks that

There is money for HIV/AIDS program in this country but we continue to die and suffer without food and unable to support our families... where does this money go? (President of Thinena association, Maputo: 2004).

This issue is very complex indeed. But despite all these disagreement between international NGOs and PLWHA associations and the members among themselves as regards funds, the activities of PLWHA cannot be undermined.

This section has shown how the epidemic has now advanced significantly in Mozambique, fuelled by labour migration, rapid urbanisation, high levels of poverty, insufficient health infrastructures and significant rates of sexually transmitted infections.

The Government of Mozambique has taken a robust stance, matched by significant international efforts to combat the epidemic. None of these have so far incorporated large-scale treatment programmes for people living with HIV/AIDS. The emphasis has been on prevention, awareness-raising, voluntary counselling and testing and palliative care.

The author looked at different institutions involved in this fight against the pandemic among which we have MONASO which is the AIDS-NGO umbrella organization funded in 1991. MONASO support the NACP in co-ordinating NGOs and CBOs working on HIV/AIDS activities. Nowadays hundreds of members are working under the guidance and support of MONASO in care and support, training of activists and peer-educators, PLWA, community mobilization, condom promotion and distribution. In each province there is a nucleus of MONASO. The most important activities carried out are: CBOs/NGOs mobilization – co-ordination and support, training for staff members, project design, Media and Government sensibilization and resource mobilization. An international NGO, PSI, is providing also technical assistance to the NACP through the implementation of a Condom Social Marketing (CSM) component.

Some private companies are participating with NGOs to facilitate IEC activities at the work place and are selling the NACP branded condom, JeitO. Around 1000 private sector commercial distributors of JeitO are currently throughout Mozambique. The World Bank & MONASO are in negotiation with many private companies for the obligatory inclusion of STD/AIDS prevention activities for the benefit of the project- workers (and communities surrounded) in the Roads and Coastal Shipping (ROCS) Project. In 1997, the UN Theme Group on HIV/AIDS has invited the chief editors of all major newspapers, radio and TV to discuss the possible roles of media in an effective AIDS program.

The Alliance has been working in Mozambique since 2001 and established a country office in 2003. It offers programmatic and organisational support to local non-governmental and community-based organisations, faith-based organisations, organisations of people living with HIV/AIDS and governmental institutions in the central provinces to respond effectively to HIV/AIDS. It enables orphans, vulnerable children and people living with HIV/AIDS to access quality care and support services through partner programmes in central Mozambique.

Mozambique is battling to contain HIV/AIDS and the government faces hard choices about funds that block access to the cheapest drugs. The Mozambican government is now one of the recipients of US President George W Bush's \$15bn Emergency Plan for AIDS. The fight against this pandemic still continues.

Having thus laid bare all these issues related to HIV in Mozambique, we now feel that the ground has been cleared enough for us to speak of the relevance of PLWHAs in Mozambique based on some history cases.

Relevance of PLWHA in Mozambique discussion

Relevance of the findings

This section is a summary of findings from the review of the author's experience on the work place and interviews with PLWHAs staff and members. Where appropriate, quotes from interviews and documents are included.

The author present first the findings related to the selected History cases's relevance, followed by PLWHAs intervention, their success and effectiveness. The report concludes with a summary of the lessons learned and considerations for the development of these associations up to 2005.

Before examining these history cases, it is important to signal that there are two views regarding the relevance of PLWHA associations: The first view is that these associations are very important because it is only through them that one is able to identify and bring HIV positive people together and assist them. Most HIV/AIDS positive people and national NGOs argue that when HIV people form (recognised) PLWHA associations, this prevents opportunists from getting money in the name people suffering from HIV/AIDS.

The second view, however, is that it does not matter whether there is an association or not because the members that are in the associations are less than the total number of people living with HIV in the country. In other words, not more than 1% of people with HIV/AIDS in the country are in these associations (INE, 2003). Therefore, people would like to see new ways of reaching HIV/AIDS infected people.

In Chimoio, a GTZ²⁰ official argues that:

'It is not important to have PLWHA associations in the country because of the financial costs which include both activities like capacity building and payments of staff members'.

She continues and argues that:

People in the board are the only ones who benefit in these associations and that many women do not see the benefits of being member of the association as they don't have key or high positions in these associations.

²⁰ GTZ it is a German Non Governmental Organization supported by the German government

Surprisingly enough the study shows the existence of GATVs in the cities even though more associations are being formed and expanding through the districts. Moreover, the testimonies of people living with the virus show clearly that these PLWHAs are of great impact in the lives of many Mozambicans if not all.

Presentation of some selected case histories

The focus here is on understanding the appropriateness and clarity of the goals and actions of PLWHAs in order to inform people about their effectiveness. The author analyzed these cases with the following questions in mind:

- Were the PLWHAs appropriate in terms of the needs and the expectations of the HIV/AIDS patients?
- Have they succeeded (at least morally) in assisting their patients?
- Were the planned goals, targets and outcomes clearly linked and comprehensive to people?

The following are some selected case stories of some HIV positive people in the associations. These stories can help us to better understand the problems faced by these people. This is to support the argument that people discover that they are HIV positive when they go to the hospital for other medical examination. Some extracts also elucidate the role played by the family in supporting their dear sick parent. Unfortunately there are examples that confirm that some times they hide their sero positive status prejudicing their partners. All in all situations, PLWHA associations helped these people in various ways to live with this disease without stress.

Case history 1²¹

Elisa aged 31, was divorced 6 years ago and is mother of two children. The oldest is 16 years, the second born is 13 years. The woman is educated up to grade 7. This woman was found at a support group called Tinhena at 1 de Maio hospital in Maputo. She told us her story:

I discovered that I was HIV/AIDS positive because from 2000, I was falling ill frequently. In 2002, I was diagnosed with Tuberculosis and the doctor advised me to undergo an HIV test because he suspected I was HIV positive. I went through the test and the results were HIV positive. I didn't believe the result and as soon as I started to feel better I dropped the treatment. A few months later, I got sick again. So I decided to resume treatment because I thought that I would die if I didn't take the treatment seriously. Now I'm feeling much better.

After getting divorced from her husband she started to work for a private newspaper as a cleaner to enable her support her children. When she fell ill she began to face problems with her employers. Her story continues:

[...] my doctor gave me a recommendation letter addressed to my office saying that I should avoid doing heavy jobs because of my illness. After presenting the letter, I lost my job, because my employers did not have light jobs for me and I was not given any terminal benefits. I took the matter to the Human Rights League of Mozambique. The case is still pending and I do not have any response yet.

I became sick two years after being divorced. I can say nothing about him. No one of my family knows about my situation. I'm afraid to tell them

²¹ For reasons of confidentiality, we will use pseudonyms (not real names) to refer to the people who gave us their testimonies.

because few months ago I lost my sister by the same disease, so I don't want to cause problems to my parents.

I live with my parents and my children. Before I lost my job, I used to help my parents with supporting the family from the little I had as a cleaner. They didn't know that I'm a HIV positive and when I fell sick I told them that I had tuberculosis.

I knew about the existence of this association for people living with HIV/AIDS group through that my late sister. I used to accompany her to this hospital and to this support group. In this support group we are all friends and we are treated in the same way

Case history 2

Jannet gives her own testimony in these terms:

I became sexually active when I was 15 year old. While I was a student I got pregnant and my partner organized the lobola.

When I got sick I was still living with my family and my husband. They took me to a traditional healer who told us that my illness was related to the payment of lobola. But since I didn't get better my husband's family took me back to my parents. Since that time, I never went back to my husband's place because he went to South Africa. But I knew that he was already sick before he left for South Africa. I am convinced having been contaminated by him. He was a polygamist with three wives including myself and had also many girlfriends.

None of us disclosed his/her HIV status to his/her partner, but I think that he started to undergo treatment and use to tell me that we will die together even if we separate from each other.

A few months ago I decided to tell my children that I am HIV positive. This was a way of warning them about the dangers of HIV/AIDS and preparing them to face the challenges of life when I will no more be there. I hope they got my message.

It is difficult for my father to look after us properly. At least he provides food and shelter. But I have to find ways to provide other things such as school fees for my children. I am now working as an activist for this support group. I hope we will have some incentive with time. Till now, we still struggle to find a financial support for our activities.

Case history 3

My name is Elisabeth aged 34 and mother of two children. The oldest is 16 and the youngest 14. I was married till my world was messed up in 98 when my husband died. When we got married, we were young and belonged to the same Christian church. We stayed together for 9 years and it was after that when my husband fell ill. I and his family thought it was a normal disease but he lost a lot of weight. When we took him to Machava hospital, he was found with tuberculosis and was admitted [Machava is a TB specialised hospital in Maputo]. When he felt better, he was discharged from the hospital and came back home. He discontinued his treatment and started drinking heavily. A few months later, he died. After my husband's death I also fell sick and was told at the hospital that I am HIV positive. Then I realised that my husband died from AIDS as well. Two years later, I had a boyfriend who was working in South Africa. I fell pregnant during the time I was there for visit. I thought of my HIV status and I realised that I had to make abortion. I asked my brother to assist me but he denied my request due to his religious belief. As a result my pregnancy grew up until I gave birth to premature twins but who eventually died.

Although I was ill during my pregnancy, my situation, however, became worse after I gave birth. I fell seriously ill, I had TB and herpes zoster. I went back to the hospital but the nurse was disappointed. She sadly remarked that I was not supposed to be pregnant knowing that I'm HIV positive. I apologised for my gaffe.

It was at the hospital where I found friends who introduced me to Tinhena association. I am now feeling better and taking the medication consistently. I love to be here because of the warmth atmosphere of friendship between us. I come here everyday. It is here where I find friends with whom we talk about our lives openly and support each other. We are comforted by the idea we have the same problem.

I am now living with the father of my late twins who also was tested HIV positive. I explained my status to him and he accepted to take an HIV test. We are living together without any problems. When I started the anti - retroviral treatment the nurse asked me to come with a family member. I took my father. (This is a condition for starting this kind of treatment in all hospitals). My husband's father helps us to support the family because both of us are not working.

Some of my family members know my HIV status but I have never told others about it.

While this story seems to have a happy ending, not all of them do.

Case history 4

My name is Jorge. I am 34 years age and have never been married but I used to have a lot of girlfriends. I stay with my brother, my sister-in-law and my nephews. My brother is the only one who is working. It was in 2000 that I started feeling that I was sick. While ago in South Africa I used to work as a security guard in a company in Gemirsten and had that privilege of going to the hospital for treatment. Despite these good efforts, instead of improving my condition was worsening. This is how I ended up loosing my job and was given money, just enough, to travel back home. In Maputo my family took me to traditional healer in Gaza province but there is no improvement.

The first and serious disease I suffered from in my life was a sexually transmitted disease. The hospitals in South Africa failed to solve

this illness. When my brother took me to the hospital I already had a lot of complications. Besides, I developed herpes zoster and lost a lot of weight. I was unable to move by my self.

I was asked by a medical doctor to undergo an HIV test and the result was positive. I was admitted and transferred to hospital “1 de Maio”. Before I started with my treatment, I was already left with 34kgs only. What a loss! I was put on an anti retroviral treatment which I have continued to take till now. Nevertheless, I regained weight and weight 68kgs now. I know for sure that HIV/AIDS is real. I have this disease because of having many girlfriends, many sexual partners. I was never concerned about safe sex. I trusted all of them, I never used condoms. See what happened now!

I was invited by the coordinator of the support group to attend the meeting after consultation with the doctor, and I joined this group. I learned quickly that that I was not the only person on earth with this problem. This is how I started attending meetings every week. Now I also invite other people to join our group.

No one in my family knows that I am HIV positive apart from my brother who took me to the hospital, therefore, I have never been discriminated against by any of my family members or neighbour what ever.

As activists we have a project to visit fellow HIV positive people at home, we are not receiving any incentive but we hope that we will start receiving that very soon. If we had some incentive, that would be good for us, we would be able to look after our families and continue to work without worries.

Discussion of Findings (case histories)

These examples of case histories are what one should consider as revealing the reality of HIV/AIDS in Mozambique. These examples also may put to rest any argument that PLWHAs are not doing a proper job in Mozambique. They prove beyond any doubt that

PLWAs associations give real support to HIV positive people in this country. These case histories, moreover, represent and continue to represent several cases of HIV peoples bad and good experiences all over the country.

In the first interview (and many others that come after) Elisa shows how she only went for an HIV test when she realised that she was seriously sick. Like her in Mozambique most people realise that they are HIV/AIDS positive only when they frequently fall ill and are advised to take an HIV test. Based on our interviews 100% of people in the associations knew about their situation because of the persistent illness. The author is, therefore, tempted to generalise that people in this country never decide to have HIV test before they can experience illness. Yet having HIV test before one is seriously sick can increase chances for one to protect himself. Researchers suggest that the proper strategy for battling AIDS is to attack the virus. Most researchers, however, believe that the best approach is to treat HIV early, since this may preserve the body's own defenses against HIV.

Reading Jannet's story in interview 2 makes the author at first glance to think of polygamy as one of the main causes of HIV infection in Mozambique. In Mozambique, HIV infection increases because husbands who usually have a number of sexual partners. It is often to hear of stories like this by Stephanie Nolen (2005) about Azarias Mateusse and his four wives. *It has been four years since they buried Azarias Mateusse in the crowded cemetery in Xai Xai, but his shadow still looms large over the little concrete house where he lived with his wives. His first wife, Anita Manhiça, 43, is rail-thin and racked by a bone-shaking cough. These days she lies on a straw mat in the dusty yard, with barely the strength to tug a faded cotton sheet around her shoulders. She shivers, although it is 30 C. Azarias's second wife, Alba Houhou, 31, is starting to feel unwell. Some days she hardly has the energy to get dressed. She sends the children to fetch water from the village standpipe. And his third wife, Gracinda Invane, 33, has read the signs at Azarias's house; she has taken her two children and moved into town. But Gracinda, too, most likely has AIDS.*

Jannett is one of those victims in a polygamous marriage, whose marriage makes her end up HIV positive. Polygamy is the most frequent and main mode of transmission of HIV. Most HIV positive persons in this country have up to four partners (if not wives).

Another issue is that Jannett has been able to reveal her HIV status to her kids. In fact, deciding who to share your status with not only is a very personal decision but also a very difficult one to take. It may be hard to know if telling certain people will bring good or bad consequences. You might fear negative responses like rejection, discrimination, abandonment, or isolation. You might worry about being judged or feel guilty about past drug use or sexual behavior. In some situations, revealing your status could put you at risk for physical harm. Since some people may not be as accepting of your HIV status, these are all valid issues to think about.

Telling kids about one's status is not a practice which is common in Mozambique where it can be associated with taboo. If you have kids, telling them about your HIV status can be even more challenging. It is like telling them about other touchy topics -- such as body parts, puberty, and sex issues. But telling them can sometimes be rewarding.

Because on the Children with infected parents are a growing group who have concerns of their own: "Who will take care of me if my parents get sick? What happens to me if they die?" So, it might help them to start imagining their own destiny in this world without parents. But this depends on age since the youngest ones (0 to 10 year old) have nothing to do for themselves.

The National Women's Health Information Center (2005) writing about *Women and HIV/AIDS* acknowledges that there are mixed opinions on how mothers should handle this difficult decision. It provides however the results of some studies which show that open communication about the illness to their kids is better than not telling them. Children may already know something is wrong; keeping the illness a secret can confuse children and make them feel anxious. Other studies, the center argues, have found that children have negative reactions to being told, like behavior problems, sexual risk-taking behavior, and lower school performance. Several studies have shown that if a HIV+

mother reveals her status, telling a child to keep her health condition a secret is stressful for that child and as a result, that child may have behavior problems.

In one study, women with HIV who told their children about their illness were interviewed. They recommended these tips for talking to your kids about your HIV status.

- Think about why you want to tell your children. Make sure you're ready.
- Educate yourself about HIV so you can talk to your children about the illness.
- Plan for what you're going to say.
- Consider how healthy you are. It might be better to talk to your child when you're feeling healthy and can show your child a healthy, positive attitude.
- Think about other things going on in the family. It may not be the best time to tell your child when there are other stresses in the family.
- After you tell your children, get them additional support. They could talk to a health professional who can talk more with your children about HIV.

With regards to the above, we see that it took to Jannett a lot of courage to reveal her status to her kids. It is left to the reader to see where, when, how, why, and whether or not do the same once found in the same circumstances.

The author is provided with other encouraging issues by *Elisabeth Ricardo* in interview 3 whereby the speaker who supposedly contaminated her husband with the virus encourages him to confirm it with a test and the later surrenders. The author is also encouraged by the example given by both families supporting them even as *Elisabeth* started her antiretroviral treatment.

Unlike most cases where they have portrayed women as sexual objects by African men, here *Elisabeth's* example forces us to believe that African men are not all unreasonable. An HIV positive man can also make his partner understand that although she might be

the cause of his misery but he does not blame her for his own mistake for having not undergone with her for test before marriage. This makes the author also to believe that all the myths, stereotypes around African men being abusive can be challenged though still happening here and there. Gender equality has been firmly on the transformation agenda in Africa. Values such as respect of women's dignity and opinions are now recognized and getting ground.

Family support as, already discussed, is very important for HIV positive persons. *Elisabeth* example is of many which show that African people are good in providing practical and emotional support to their family members in pain no matter how the disease was contracted. (e.g. individuals living with HIV or AIDS). What they need maybe is a frame where a range of special services or training to those affected by their loved ones having HIV or AIDS so that they can now what exactly to do when the subjects undergo treatment, how to handle them.

In Interview 4 *Jorge* goes for traditional leaders to cure HIV/AIDS. It was also observed that some of the respondents consulted traditional healers at the same time that they are undergoing treatment in their respective hospitals. It is still believed by some people in Africa that HIV is caused by witchcraft or sorcery therefore *Sangomas* (traditional healers) or traditional healers are the only ones who can handle or solve such problems. This is easily rejected by science which believes that HIV disease has nothing to do with spirits intervention and therefore see it as a merely body disease. Whether this African belief is based on metaphysical dimension is a result of their ignorance or not, it remains, however, true that some people confess openly that traditional treatment is worth it.

AIDS action (2004) argues that 'western' or 'modern' medicine can reduce levels of HIV in the body and treat HIV-related opportunistic infections, but many people with HIV have no access to even the most basic western medicines. It is estimated that in many developing countries, particularly in rural areas, four out of every five people visit traditional health practitioners and use traditional treatments.

Traditional healers already treat large numbers of people living with HIV and AIDS. It is important to look at approaches to working with traditional health practitioners that can

improve HIV prevention and care services, while continuing to advocate for improved access to western medicines and treatment.

Some programs have trained traditional health practitioners in HIV/AIDS and other sexually transmitted infections (STIs). Appropriate training encourages traditional health practitioners to replace harmful practices or myths about HIV with safer practices. It can also help them to diagnose HIV and other STIs and encourage increased collaboration with biomedical or 'western' health services. This collaboration can have a number of advantages and biomedical health practitioners also need education in the benefits of working with recognized traditional health practitioners. For example, traditional health practitioners often have an approach to healing that takes into account the whole person - their mental, emotional, spiritual and physical health. Initial research into a variety of traditional treatments also suggests that some of these treatments offer potential relief from HIV-related infections; although like western medicine, none of these treatments is a cure for HIV.

This issue proper referring of *AIDS Action* looks at some successful approaches to working with traditional health practitioners and using traditional health practices to improve HIV prevention and care.

The traditional healers should be perceived as educators. This is so because respected traditional health practitioners see many clients and they can be very powerful educators. They have influence in the community, as well as with other healers through their professional networks. They understand local belief systems and can explain illness and misfortune in ways that people understand. It is important that they have correct information about HIV/AIDS and other sexually transmitted infections.

This paper argues that many people with HIV approach traditional healers even when they have access to other health services. One reason is that traditional healers usually treat the 'whole' person, not just the disease. They take into account a person's mental, emotional and spiritual as well as physical well-being. This can include contacting the spirits for help.

Traditional health practitioners often see their patients together with other family members and can play an important role in family counseling and in reducing stigma and discrimination against people with HIV/AIDS.

A quick look at these stories also revealed that what most of them share in common is that they often fail to disclose their HIV status (except to one case story). Most of the people interviewed confirmed that they did not tell any one of their family members that they were HIV positive until they started taking ARVs. This problem is related to discrimination and stigma. Similarly all complain about poverty and being unable to look after their family.

Finally, they all acknowledge the help they got from the support group or PLWHA associations. This frame provides a contact point and meeting place where HIV people get together and talk through their thoughts, fears, worries and frustrations without being faced with the stigma associated with the illness.

In short, people living with HIV/AIDS (PLWAs) can live positively with HIV longer if they talk openly about their problems and share information with others. Keeping HIV a secret could make those who are infected feel unhappy and stressed. Such emotional stress weakens the immune system. Disclosing (sharing) one's HIV status with someone else can help people get counseling, and help them get connected with others who are HIV-positive and able to provide support. In addition to people with HIV attempting to talk more freely, the entire community and religious leaders can contribute to the fight against HIV/AIDS by avoiding stigmatizing those with HIV and cooperating with each other to address the problem.

Conclusion

In this chapter the author has shown how HIV organizations have developed from support groups into associations. This was out of the need of becoming formally structured, be legally recognised by the ministry of justice and also to reach more people. It was believed that only associations could achieve these goals. The feelings, sentiments and desires of HIV people or PLWHAs members, their struggles and happiness in life both as individuals and members of PLWHAs were clearly expressed and presented in

this chapter. Most importantly, among their problems lays their need of being accepted in the society. The social responses of fear, denial, stigma and discrimination which have accompanied the epidemic for a while need to be dealt with. HIV people should not be denied access to the services and treatment they need. In Mozambique where HIV and AIDS are believed to bring shame upon the family or community, we insisted that good policy or law should help combat HIV/AIDS related discrimination.

Gender inequality was raised as one of the main cultural issues related to HIV in African and particularly in Mozambique. In this chapter, the have provided an overview of the gender-based abuses in this country that fuel the HIV/AIDS epidemic and make the lives of women and girls already living with HIV/AIDS unbearable. The argument was based largely on the horrifying stories told by women and girls who have suffered abuse from their husbands and in-laws. Through stories and voices of the women and girls and through research, the report illustrates the inter-linkages between human rights violations of women and girls and the HIV/AIDS crisis. It is hoped that an understanding of the human reality of these abuses will lead to greater protection of the rights of the girls and women at the center of a deadly epidemic.

The also spoke about fund raising. PLWHAs struggle to have funds though some efforts made by donors such as World Bank and others to support them. In fact, the author recommend that those HIV organizations (PLWHAs) that are serious about fund raising must also be committed to developing a rapport and reaching out to potential donors. Building relationships with donors, potential donors, local community and local government are essential. The more these organizations are kept informed, the higher the chances are that they will continue their support. The author also suggested that honest communication between the organizations and the donor can improve the lives of the sick people.

The author ended this chapter with case histories where analysis was made on some testimonies of HIV +people. It has been observed that people living with HIV/AIDS (PLWAs) can live positively with HIV longer if they talk openly about their problems

and share information with others. Keeping HIV a secret could make those who are infected feel unhappy and stressed.

CHAPTER 6 - CONCLUSION

Recapitulation of key issues

HIV/AIDS is a new holocaust that reaches all people independently of race, religious, sex, age or social position. The consequences of HIV/AIDS can be far-reaching for young people. Not only does HIV disease have terrible consequences for the individual, causing serious illness and eventual death, it has the potential to trigger negative social reactions. Across the world, people with HIV/AIDS routinely experience discrimination, stigmatization and ostracization.

The intrinsic problems posed by this pandemic constitute a new challenge. The increasing number of people infected by HIV/AIDS in the world has forced the infected people to be organized in groups or associations in order to face together the challenges of living with HIV/AIDS in the society.

The associations of PLWA and its members face many problems such as discrimination and stigma that is attached to the scourge. But notwithstanding these problems, these associations are showing an incredible dedication to addressing the issue of HIV/AIDS.

In Mozambique, the associations have specific and unique problems that are linked to the realities of the continent. These problems include poverty, illiteracy, cultural stereotype and many more. Despite the fact that many associations, in Mozambique as in other parts of Africa, are experiencing difficulties; some associations have done very well in their work. For example, the South African and Ugandan associations have so far demonstrated that they are capable of defending the interests of their members. For Mozambique, however, there seem to be no definite improvement to HIV/AIDS issues in Mozambique despite the good work which is undergoing there under the PLWHAs. The legal future of this population is unpredictable, it is less certain, but the author believes that, at least for the therapeutic aspect, a big part of HIV population, efficient comfort from these PLWHAs associations has been obtained.

In the three provinces where this research was conducted evidence revealed that the associations of PLWHA are a new phenomenon, where the members are looking for their own space in order to tackle the problem that is being posed by HIV/AIDS.

This research tried to disaggregate the experiences that are pertinent to these associations and give a voice to people in these associations. Most of the time, matters of HIV/AIDS have been ranked as least priority. This investigation of PLWHA associations which was conducted in three different geographical areas in the country showed more similarities than differences. These differences and similarities were within the association itself, the day to day running of the association, and the relationship of these associations with government institutions and civil society.

The study found three major modes of heterosexual transmission, transfusion and mother to child. The risk factors are: poverty, migration (miner), population movements, refugee return from countries with high HIV prevalence, high prevalence of STD in young people, resistance to condom use, economic dependence of women, and also lack of information, illiteracy and disbelief.

The research reveals, furthermore, that there are no significant differences between HIV/AIDS associations in these three provinces. There are more similarities than there are differences. They share in common unemployment, low level of schooling, uncontrolled urbanization, prostitution, lack of resources to support their family members, etc.). Other types of similarities are shaped by patterns of formation of these associations which were similar and may have been formed by the same people. However, in Maputo which is the capital city, due to the favourable conditions there, these associations and support groups are more developed and dynamic than in other provinces. It would however be interesting to find out how HIV/AIDS positive people in rural areas are responding to the problem of HIV/AIDS.

It is also worth remarking that HIV geographic distribution is uneven in the country. Central provinces (Manica, Tete, Sofala, and Zambezia) are more affected than the Northern and the Southern Provinces. The trends follow the major transport routes and the areas bordering Zimbabwe, Malawi and Zambia. In these areas of the country, many

factors, in the past, have contributed to increase HIV/AIDS infection and other are fuelling the spread of the epidemic (unemployment, low level of schooling, uncontrolled urbanization, prostitution, e.g.).

The study also found much variation or inequality between men and women around the issue of sexuality displayed by gender roles. For women and adolescent girls, the consequence of AIDS can be particularly dire. There is strong evidence, for example, that in African countries (e.g. Mozambique) women are often "blamed" for HIV disease even in circumstances where they have been infected by remaining faithful to their husband or other male partner. There is also evidence to suggest that women are less likely to receive the kind of care and support made available to male household members (Warwick et al., 1998). Moreover, where the male head of household has died there is sometimes loss of social support for young women, ostracization from the community, and lack of legal protection to inherit land and property.

The gender inequality is mainly confirmed by the reaction of men towards HIV test. It is said that when a woman is diagnosed with HIV/AIDS first, she does not get support from the husband or his family because the tendency is to blame her for contracting the disease and she may end up being returned to her parents. On the contrary, if the disease is detected first in the man, the wife will normally support him till his death even though she may be accused by her husband's family of bewitching the husband.

This study found that HIV positive women face difficulties when it comes to following the teachings of vertical transmission programmes because they lack the capacity to feed their babies with artificial milk. They feel obligated to breast feed their children because their families expect them to do so. In this regard, women are faced with difficult decision of disclosing their HIV status. On one hand, if they disclose their status they face the risk of being chased from home and, on the other hand, they face the risk of transmitting the virus to the baby if they breastfeed their child.

In Mozambique there are two different types of associations of people dealing with the problem of HIV/AIDS. These include support groups and PLWHA local association. Support groups are the informal groups that are not legally recognized by the Ministry of

Justice, while PLWHA associations are formal organizations and are legally recognized by the government. Nonetheless the objectives and most important activities are the same in both forms of organization. Most members joined the associations and support groups after being invited by the other members working as activists in hospitals.

This research argues, however, that lack of adequate knowledge about HIV/AIDS, fear of infection, the stigmatization, put these associations at a disadvantage in coming out to speak about their HIV/AIDS status and its associated problems.

This research accepts also the fact that members in these associations are firstly concerned with gaining material and financial support although sharing experiences and mutual consolation among members remain the ultimate goals. Most members of these associations are people who have HIV and are who lack economic means to have a better living. Therefore they are weak and have problems with performing their jobs.

The income-generating activities run by these associations are not sustainable because of stiff competition. There are too many NGOs doing the same income, generating activities making it too hard to market products produced. Another weakness is that they lack initiatives and the capacity to negotiate with donors for long term sustainable project.

The context of poverty, dependence, superstition, illiteracy, unemployment, violence and an overall sense of doom plays a role in sexuality and sexual and interplay amongst the poor, shaping their responses and, as shown in this thesis, their inability to protect themselves in the face of this pandemic. This highlights the fact that HIV/AIDS is a different reality for the rich and the poor people. In this regard, poor people in these associations do not have the means to support themselves and their families, while rich people have means to themselves and their families and can afford treatment in private clinics.

In Mozambique prominent citizens living with HIV keep their status hidden and are not involved in HIV/AIDS information awareness campaign in the associations of PLWA. This could be because of the fact that HIV/AIDS is seen as a disease for poor people. The

stigmatization of HIV/AIDS has become so high that people infected with the disease deny any association with this epidemic.

It was also realized that rich people experienced confidentiality with issues relating to HIV/AIDS when compared to poor people. This is because while poor people have to go the associations to deal with his/her reality, rich people have options of private clinics.

It should be added that poor members of PLWHA associations regard themselves as near death since they do not have access to antiretroviral drugs and other resources. They believe that their way of life changes after being diagnosed HIV positive they feel discriminated against and alienated by their families and their communities.

It was also discovered that most members of the associations did not disclose their HIV/AIDS status to their partners and families. They behaved as though they are not HIV positive and continued to have many partners. Women continue their reproductive cycles and breastfeeding despite attending the PTV Programa de Transmissao Vertical 'Transmitted Vertical Program' where they are through how to avoid the vertical transmission. The reason behind is that the fame of having a baby or being called mother of *xx* or *xy* (baby's name) is in Africa much more valued (even if the baby eventually dies later) rather than not having one.

This study showed that there are more women than men in PLWHA associations because women are found to have HIV/AIDS virus when they attend consultation related to their reproductive health. Women in these associations normally do not assume high positions and therefore it is difficult for them to address their major concerns. Men usually occupy executive positions. The traditional attitudes of gender inequality which consist in men always occupying dominant positions are reflected in the associations.

The research also showed that family members bear the burden of caring for the sick and their dependants and have the potential to do so even though they are sometimes failed by their limited resources. When a family member is HIV positive, it entails a high burden on his family because they have to support him/her under high level of poverty, increasing unemployment, deterioration of household income, and rising cost of living,

and poor coverage of health services. But there is sometimes little involvement of family members in the activities of PLWA associations due to lack of information. And some get interested only when their family members are about to start ARV treatment as required by PLWHA. Before a patient begins with his/her ARV treatment, a member of the family has to be briefed on the consequences of undertaking this treatment.

It is sad to remark that the increasing number of *GATVs* in the country is not accompanied by increasing level of knowledge of the HIV/AIDS pandemic. The number of people who undertake voluntary testing for HIV/AIDS is insignificant. Moreover, the only service provided is HIV/AIDS testing for people suspected of having the virus by the hospital.

Mozambique is passing through a difficult time in that beside the HIV/AIDS pandemic, the Government has to deal with other national issues which divert government attention on the problem of HIV/AIDS. In addition to the above, the adoption of the new liberal policy to reduce the intervention of the state in social welfare, health, and education impacts negatively on the fight against HIV/AIDS. Nonetheless the government does intervene on a small scale through the CNCS and the Ministry of Health. This is illustrated by increasing number of *GATVs*. The approval of antiretroviral policy is a good example of the interventions of government although many people also die from the treatment's side effects.

These findings revealed that the relationship within associations and between the various stakeholders is not always harmonious. Weak partnership among NGOs working in the field of HIV/AIDS, competitions for funding, and disagreements among the members of these associations are some of the problems that hinder the successful implementation of HIV/AIDS programmes. Most of the associations acknowledge that their organisations are weak and that; they lack human and financial resources to efficiently and effectively implement programmes. However the National networks of HIV/AIDS has made efforts in trying to solve this common problem jointly in the last few years.

Recommendations

On basis of the findings of this research, the author would like to make the following recommendations:

Given the fact that less than 1 % of People Living with HIV/AIDS in Mozambique are members of these associations, there is a need to do more work to integrate more people in these associations by mobilising people under VCT and, if they are found HIV positive, to encourage them to have access to associations, or perhaps even compel them to join as a condition for receiving ARV treatment.

HIV health care services and activities of PLWHA association should be extended to people affected with HIV/AIDS in the rural areas.

Government, civil society and the media should step up its efforts of reducing discrimination and stigmatization of PLWA through information campaigns. They should also redesign the messages in the information campaigns to ensure that they reach achieve the targeted audience, and add messages that promote PLWA associations and the benefits of joining them.

It is important to have a national welfare policy which will mitigate the problems of people infected and affected by HIV/AIDS. Particular attention should be paid to vulnerable groups like children who have been orphaned as a result of losing parents through HIV/AIDS. The government should take the responsibility of supporting HIV/AIDS positive women by providing milk and other food for their babies until they have grown up. Above all, reducing poverty should be one of the effective ways to deal with HIV/AIDS.

Prominent citizens in Mozambique should be mobilized to take an active role in the fight against HIV/AIDS. If they are infected they must come in the open and declare their status and get actively involved in the associations of people living with HIV/Aids in Mozambique. By doing this they will change the mentality of poor people who view AIDS as a disease for poor people.

NGOs and CBOs should strengthen their internal organizational structures and broaden their networks through forming partnership with other NGOs dealing with this issue. The increased efficiency in terms of service delivery and partnerships will strengthen their collective voice and make it easier for them to share resources, to work with other non-NGOs actors, and to lobby with the Ministry of Health Ministry and other institutions.

The author would like to call upon the government of Mozambique to increasingly involve PLWA in responding to the HIV/AIDS pandemic.

The government in conjunction with other stakeholders involved in the fight against HIV/AIDS should come up with a strategy that will encourage its citizen to undergo routine voluntary testing and counseling for HIV.

Government in conjunction with other stakeholders involved in the fight against HIV/AIDS should be more efficient and effective, thereby reducing the negative effects of bureaucracy. The government should mobilize more resources so that all HIV/AIDS infected people may have access to ARVs.

Given the challenges of the HIV/AIDS epidemic, the government and civil society need to pay attention to the plight of these families who usually have limited resources and are faced with the task of dealing with this problem.

The challenge of associations in Mozambique, therefore, is to recognize these weaknesses and to find means and strategies for overcoming them in order to reduce the impact of HIV/AIDS in the country.

Significance of Findings

These findings have significance for the discipline (anthropology) because they show that although much progress has been made to integrate HIV issues into our discipline, but much more still needs to be done. As a whole, anthropologists need to work much more effectively to produce, and publish more about HIV/AIDS. The findings also illustrate great differences between the creation and maintenance of PLWHA associations. There is a great discontentment from the members as regards to the management as they believe

that those in positions of power misuse the money. This money does not profit everybody. The author is of the opinion that this claim is worth consideration and that those engaged in business of HIV organizations need, and would consistently be, more concerned about the well-being of those whose rights and needs they claim to defend. A 'poor' quality service hosted by a business such as this one can generate immediate negative feedback from HIV people. If these poor people continue to express their dissatisfaction with services offered they may feel penalize both sides by the disease on the one hand and mentally and emotionally on the other hand.

Limitations and Future Research Opportunities

This study has hinted at a number of research areas which merit further study. In the area of retroviral treatment, it would be helpful for there to be an ongoing effort to evaluate whether this treatment helps or does not help Mozambicans. Researchers need to see on a continuing basis the side effects of these drugs. Another issue is that of structures that need to be put in place for HIV children or orphans left behind by parents who died with HIV to grow from with family love.

The idea of extended family that needs to be supported financially as they might wish to foster these children is a great idea but which requires further investigation. We think that PLWHA need to include such a project in its program as well. Surely there will be improvements and even greater improvements in the future if this project is given thought.

There should be additional research work to compare the PLWHAs operational, and informational enhancements of HIV education programs in urban areas with those operated by these organizations in the rural areas. The lack of knowledge or information in these rural areas demands it. Yet, the current research has illustrated areas in which the PLWHAs services are more advanced although it did not cover the whole country. Perhaps additional research work with larger populations would help in this regard.

There is clear evidence that PLWHA well-designed programs of sex education, which include messages about safer sex as well as those about abstinence, may delay the onset of sexual activity, and reduce the number of sexual partners, and increase contraceptive

use among those who are already sexually active). Here again, further ongoing research is warranted to see to what extent sex education's applications are important for HIV positive and negative people.

The current research has barely scratched the surface of what is obviously a concern of many international donor Institutions and NGOs. A reading of the written survey responses by our interviewees shows that there are clearly many financial problems related to mismanagement of PLWHAs or lack of transparency as far as the funds are concerned. A clear relationship has already been established between PLWHAs and their international donors on HIV issues; they must continue to build this relationship (foundation) so that it can save the lives of millions of people hit by the virus. How can the structure be altered as to meet the objects originally designed for the associations? This is the question that must constantly be asked and addressed to the stakeholders and more especially the leaders of the PLWHAs.

All these issues are important in a general sense in that their investigation will help us better explain our world and the people living with the virus. But the issues are critical to the future survival of the PLWHAs associations, which have themselves been threatened in many ways in the recent past. If we are to be the true researchers that Africa needs, we can possibly be in the research effort we make along these lines that must continue and be able to create effective strategies now to fight against HIV/aids in the years to come.

In short, the research effort was limited initially by a lack of theoretical development in the literature. Previous works did not provide enough linking materials on HIV to The case study of PLWHA, its creation and maintenance of its programs as evidenced by the interviews. While the methods used here are reliable, and the means of measurement appear valid, the concepts involved have not previously been investigated elsewhere and should be subject to further study.

This research was not intended to make claims about discussing the entirety of all the problems pertaining to HIV disease. Rather, the research was aimed at making generalizations about HIV as dealt with by PLWA associations in Mozambique, how they help those who are infected and affected by HIV. This research supports the work

that PLWHAs association do save lives of people. Whether PLWHAs have succeeded or not is another issue and the reader may draw his/her conclusions from the work.

Recommendation for further research

It could be important to find out how other HIV/AIDS positive people out of the associations follow the life of these associations. The institutions dealing with this issue have to investigate how they can work with other informal associations based in the communities and religions. To extend the study at level of rural areas, as a way to explore what the local institutions do in this context. Why these associations are only concentrated in the cities? As we live in the time where people migrate from rural areas to big cities in search of better opportunities of life will not be the cities invaded once more by HIV if considerable efforts are not made to contain the disease both in the cities and rural areas? Further studies are needed to explore all these areas. Above all as Monteiro suggest is important to accept the perceptions of multi voices approach in this matter of HIV/AIDS in Mozambique.

This study revealed that a number of significant socio- cultural factors had an impact on HIV/AIDS situation in the three provinces. But it didn't gather evidence showing how these different factors impact in HIV/AIDS context. For instance data from INS Instituto Nacional de Estatistica ' National Institute of statistic' concerning to HIV/AIDS prevalence in the three regions of the country, indicate that the Northern Region has a low level of prevalence. It may be important to undertake a study in this region where Muslims are predominant.

It would also be interesting to find out why other HIV/AIDS positive people are not members of these associations dealing with the problem informally and not through associations, for example at household level, community level, church level etc.

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Appendix

(1) List of Acronyms and Abbreviations

AIDS- Acquired Immune Deficiency Syndrome

AMODEFA- Associacao Mocambicana do Desenvolvimento da Familia

CBOs- Community Base Organizations

CEA-UEM- Centro de Estudos Mocambicanos Universidade Eduardo Mondlane

CNCS- Conselho Nacional de Combate ao SIDA

FDA- Food and Drug Administration

FDC- Foundation for Development of the Community

Frelimo- Front of National Liberation Movement

GATV- Services of Counseling and Voluntary Testing

GTZ- German Technical Cooperation

HIV- Human Immunodeficiency Virus

ICW- International Community of Women Living with HIV/AIDS

INE- National Institut of Statistic

Kindlimuka- A National Organization of People Living with HIV/AIDS

MISAU- Mozambican Ministry of Health

MONASO- Mozambican Network of AIDS Service Organization

MPT1- Medium Term Plan

MSF- Medicos sem Fronteiras

MULEIDE- Mulher Lei e Desenvolvimento

NACP- National AIDS Control Program

NAPWA- National Association of People with AIDS in South Africa

NGOs Non Governmental Organizations

NPCS- Provincial Nucleon Against AIDS

PLWHA- People Living With HIV/AIDS

PLWA- People Living with AIDS

PMA- World program for Food

PNUD- Programa das Nacoes Unidas para o Desenvolvimento

PVOs- Private Voluntary Organizations

RENAMO- Movement of National Resistance

RENSIDA- National Network of Associations of People Living with HIV/AIDS in Mozambique

SAT- Southern Africa AIDS Training

SIDA- AIDS

STI- Sexual Transmitted Disease

TARV- Ante Retroviral Therapy

TASO- The AIDS Support Organization in Uganda

UNAIDS- United Nations Agency for AIDS

UNDP- United National Development Progr am

UNDP- United Nations for Development program

UNICEF- United Nations Children's Fund

USAID- United States Agency for International Development

VTC- voluntary Counseling and Testing

WHO- World Health Organization

WLWA- Women Living with AIDS

Guide of the interviews for the different target group

Specific questions directed to members of the board of the associations

Here major emphasis was put on understanding the many issues that can be divided into 3 sections, as follows:

- What has motivated the creation of the associations? Who, how and when they were created?
- How do they do function?
- What type of structure do they have?

The way members adhere to the associations as well as the membership requirements; member's rights (benefits) and obligations; their funding sources; the way associations interact,

Both in the country and outside.

- Difficulties encountered (relationship among members and with other members of the civil society, governmental institutions and financial support).

PLWHA who are members of the associations

Concerning this target group, it's maybe also important to find out what actually motivates people to join those associations.

- In what circumstances and how do they learn about the association's existence and mission?
- Why do people become member?
- What are the advantages and disadvantages in being a member of such kind of association?

- Do they receive some kind of advice?
- Are their family members aware of their individual membership status towards the associations?
- How do their family and other members of society in general react to this situation?

Officers of the local and international NGO's dealing directly with these associations:

- When did they start working jointly with these associations?
- What kind of partnership do they develop with these associations?
- Do they develop specific activities? What kind?
- What are their impressions about PLWHA's associations?
- What are their major difficulties in dealing with the associations?
- Apart from these associations, which other partners do they have?
- What are the differences between the associations?

Governmental institution's representatives working with the associations

It is perhaps important to get to know the government's position towards matters related to People Living with HIV/AIDS in the country, because they are the most important decision-making bodies. It seems also relevant to find out the kind of strategies they draw on in dealing with the HIV/AIDS pandemic, particularly with people already suffering from AIDS. Questions including:

- What kind of support do they give to the associations?

- What are the challenges being taken by the government towards minimizing the impact of the disease?

What type of activities do they develop in these contexts?

**A Comparative Study of Associations of People Living
With HIV/AIDS in Mozambique: The case of Maputo,
Manica and Zambezia provinces**

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A dissertation Submitted at School of Social Anthropology, University of Witwatersrand,
Johannesburg, in Partial Fulfillment of the Requirements for the Degree of Masters of
Humanities and Social Sciences, Department of Anthropology

Johannesburg, 2005

Declaration

This thesis is entirely my own work and has not been previously submitted as a research project, dissertation, or thesis, at any other University

.....

Elisa Maria da Silveira Muianga

January 2006

University of the Witwatersrand

Dedication

To my children Neusa Tania da Silveira Chitsonzo and Ivan Maximiano da Silveira Chitsonzo and my parents.

Acknowledgements

I would like to thank to my supervisor Prof. Robert Thornton for his guidance during the elaboration of this thesis.

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I also owe a particular debt to my family especially, my father who always been a source of support. My mother, sisters, colleagues and friends, whose moral support and love made it possible for me to complete the course.

Deep thanks go to Rensida staff, PLWA Associations (in Maputo, Chimoio and Quelimane), MONASO, CNCS, FDC, Hospital Dia and others in (Maputo, Chimoio and Quelimane) for providing me helpful information for this study.

Thanks to all members of the different associations of PLWA in Mozambique especially those located where I carried out the study in Maputo, Manica and Zambezia province.

I would like to thank Kellogg's Foundation and AED for the scholarship and research fund that made it possible for me to realize this thesis. I could not be happy without addressing my thanks to CEA/UEM, the institution that gave me the opportunity to continue with my studies.

Abstract

This study was inspired by the need to develop awareness about what is going on in Mozambique regarding to the issue of HIV/AIDS. The research examined how and why the organizations of PLWA (People Living with HIV/AIDS) in Mozambique are emerging and developing, compared the particularities of the existing organizations of people living with HIV/AIDS in three province of this country (Maputo, Manica and Zambezia), and finally examined how they function, and interact with governmental and non- governmental institutions.

The study made use of the ethnographic method to design and generate a rapid "picture" of the social culture around this HIV community. The focus on this method provided further in-depth qualitative insights. Behavioral surveys were designed to provide rapid key data on sexual behavior, condom use and STI¹s. Together, these sources of data provided a spatial, quantitative and qualitative overview of the research.

The results from this study turned that the associations of PLWA and its members face many problems such as discrimination and stigma that is attached to the scourge. But notwithstanding these problems, these associations are showing an incredible dedication to addressing the issue of HIV/AIDS.

In the three provinces where this research was conducted it transpired that the associations of PLWHA are a new phenomenon, where the members are looking for their own space in order to tackle the problem that is being posed by HIV/AIDS.

The research reveals, furthermore, that there are no significant differences between HIV/AIDS associations in these three provinces. There are more similarities than there are differences. The associations have in common issues such as unemployment, low level of schooling, uncontrolled urbanization, prostitution, lack of resources to support their family members, etc. Other types of similarities are shaped by patterns of formation

¹ Sexual transmitted infections

of these associations which were similar, what invites one to think that may have been formed by the same people.

As combating HIV/AIDS seems an important tool in poverty eradication, Government, civil society and the media should step up its efforts of reducing discrimination and stigmatization of PLWA through information campaigns. They should also redesign the messages in the information campaigns to ensure that they achieve the targeted audience, and add messages that promote PLWA associations and the benefits of joining them.

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CHAPTER 1 - Scope of the Research

HIV 'community'

Our world today is one in which organizations are designed and created as tools that help those living with HIV/AIDS. It is one of the greatest challenges for our times. The fact that biomedicine has not been able to come up with a cure for AIDS has aggravated the association of this disease with stigma, discrimination, denial, shame, fear, silence and death.

HIV/AIDS: Acquired Immune Deficiency Syndrome (AIDS) is the result of an infection with the Human Immunodeficiency Virus (HIV). This virus attacks selected cells of the immune, nervous, and other systems impairing their proper function.

According to UNDP every 6 seconds, someone becomes HIV positive. The increasing number of people infected daily by HIV/AIDS in the world has, on the other hand, pushed people organize themselves and put into place existing structures to help to some extent people living with HIV/AIDS. (PNUD: 2004)

Mozambique has one of the highest HIV positive rates in the world. About 16, 2% of the adult population (15-49 years) is estimated to be HIV positive. There are about 500 new infections per day. About one million of people are HIV positive (MISAU: 2005).

This constitutes a large HIV community, that like others communities such as ethnic, economic, religious, found reasons to organize themselves to respond their eminent needs.

In this study, the term 'community' means first 'HIV community'; and being a member of it has different meanings in a practical sense to different people. To some it means people living with the virus, to others it means all those who are interested in HIV issues, while to others it means organizations such as PLWHAs.

PLWHAs understand their membership in terms of rendering specific services to the community or giving financial, moral or intellectual support.

Aims of the research

The aim of this thesis is to examine how and why the organizations of PLWA in Mozambique are emerging and developing, compares the particularities of the existing organizations of people living with HIV/AIDS in three province of this country (Maputo, Manica and Zambezia), and understand how they function and interact with the governmental and non- governmental institutions. The present study also seeks to document the impact of the disease on people relationships, by looking at how the subjects of the study interact with other socio-cultural organizations such as families in their lives. Another important aim of the study is to map the experiences of the associations in the three provinces studied, as a way to understand the subjects' experiences (those living with HIV-AIDS into the associations) in Mozambique.

In short, this thesis seeks to show how the subjects of the study battle with HIV and difficulties inherent in this struggle through the associations that support them. It is in this context that author seeks to give voice to those people who have been marginalized by their HIV status and stigmatization.

Research questions

In support of the research aims formulated in the paragraph 1.2, the following research questions will be researched.

- How and why the organizations of PLWA in Mozambique are emerging and developing?
- What are the similarities and differences among organizations of people living with HIV/AIDS in the provinces of this Maputo, Manica and Zambezia?
- How do these organizations function and interact with the governmental and non-governmental institutions?

- What is the impact of HIV/AIDS on people relationships, concerning to how the subjects of the study interact with other socio-cultural organizations such as families in their lives?
- What are the experiences of the associations in the three provinces studied, concerning to dealing with people living with HIV-AIDS in Mozambique?
- How do the subjects of the study battle with HIV and difficulties inherent in this struggle through the associations that support them?

Benefits

If readers and researchers explore the nature of research questions fully:

- The research project has more chance of fitting in smoothly with the plans of this association;
- Other associations and researchers are likely to learn from the process as well as the outcomes of research projects; and
- These associations, the government and researchers will be able to consider the implications of research for practice over a longer period.

Theoretical Framework

The topic of this thesis concerns organizations of people living with HIV/AIDS in Mozambique. This topic could be viewed within the framework of “civil society” which could be complemented by the others concepts such as social movements. Considering that this study was been done in Mozambique where the PLWA associations fall in the category of NGOs, the concept of NGOs will be also discussed.

Controversially, it has been observed that there are several conceptual definitions of civil society. Which entities what should be considered as civil society and its relation to the state? This concept is contested. Social scientists too have a problem defining civil

society in a precise and concise manner. The concept has attracted different perception and meaning. In other words, there is no consensus on the exact meaning of the term. In this study the Kaviraj's definition can fit well, when he argues that civil society is "an organized institution standing outside the state's legal *jurisdiction*, which undertakes and finds a response to specific matters within the social, political economic domains". (Kaviraj *et al*, 2001). In this perspective, different kinds of organized groups of people such as associations can fall in this category.

This concept of civil society can be reinforced by embracing the another key concept, that of Social Movement, understood as a collective action, made by an informal group(s) of people of different social categories usually excluded from history who begin asserting themselves as historical actors. Normally they are committed to broad change at the levels of individual behavior, social institutions and structures. Examples include social movements of women, ecologists, gays and others which have played a role played in social and political changes through the world.

In this regard the HIV/AIDS community can be seen in the category of excluded group considering the deep stigma and discrimination associated with this disease.

Altman argues that according to the level of organizations and commitment these movements can achieve important goals. He took the example of a gay movement that managed to influence governments and the society to develop a sense of identity among its members. (Altman, 1989:30).

The organizations of PLWHA in Mozambique can be regarded as a way of responding to specific matters of concern in the world by a group of NGOs (NGO is an acronym for non-governmental organizations that cover a whole range of organizations from e.g. small local environmental pressure groups to large international human rights organizations).

- They must be non-violent groups.
- They must not want to replace the incumbent government- they should not be political parties or opposition groups.

- They should support the aims of the organizations which recognize them (Berg, 1998: 12).

The movements of civil society play an important role in the fight against HIV/AIDS. However, attention should be given to the fact that a civil society is not above in this battle. In Uganda, for instance, they work side by side with governmental institutions. The country's authority calls for full involvement of CBOs, NGOs, donors and religious institutions (Thornton, 2003a; 2003b).

Controversially, in South Africa, the civil society, in the context of HIV/AIDS, appears to be an opposition force to the government, and puts pressure on the government to force it to pay more attention to this concern. In Mozambique civil society pleads with the government and complements the work of the government.

Using this theoretical framework, I will analyze, examine and assess their effectiveness of the role of these organizations in the context of Mozambican civil society.

Given the wide spread of HIV/AIDS in the world, and Africa in particular, the number of organizations dealing with this pandemic especially associations of people living with HIV/AIDS is increasing everyday.

This phenomenon, which opens ways for '*groups directly affected to organize themselves*' (Goss *et al*, 1995: 6), can in some way be justified by the relatively limited government intervention. The UN's secretary general, Koffi Anan assumed this same position during an interview with the BBC News answering to the question on whether he was winning the battle against HIV/AIDS, his response was that: "*I am not winning the war because I don't think the leaders of the world are engaged enough*" (in <http://www.news.bbc.co.uk/2/hit/Africa/3244564>).).

People living with HIV/AIDS seek to organize themselves in associations as a way of sharing their difficulties, fighting against common enemies, giving each other emotional and spiritual support and practical assistance (Kaleeba *et al*, 2000). That is why the author personally found it important to undertake this study and see to what extend the existing three associations of PLWHA in Mozambique follow the objectives above.

Mozambique has got three PLWHA organizations so far. In mid 1990's the first one was created in Maputo city. A few years later, two other associations emerged in Chimoio city (Manica province bordering with Zimbabwe and in Quelimane city (the Zambezia central province), respectively (MONASO²: 1999). These associations operate only in the province's capital cities.

As a Mozambican, I have interest in undertaking this case study because in Mozambique, according to available reports, stands among the sub-Saharan countries with the highest number of people infected by HIV/AIDS. However, the number of associations of people living with this infection in the country is assumed to be far less than expected; in addition to this, most people likely prefer not to adhere to those associations, or even to be aware of the advantages of being a member. The fear of being discriminated and stigmatized by the society could be the most important reason.

This study will assess the importance of these organizations dealing with PLWHA.

Methods and techniques

This study was undertaken following a *qualitative ethnographic methodology*. This methodology was adopted because the study is an exploratory study. It examined specific sites, comparing small groups in order to bring out perceptions of the people involved in these organizations and their major concerns, such as:

- The people's motivations for creating the organizations of PLWHA in Mozambique
- The functioning or organizational structure PLWHA organizations
- The organizations funding sources, and
- Their major constraints

² MONASO is a network of HIV/AIDS organizations in Mozambique. It incorporates all sorts of organizations dealing with HIV/AIDS.

The study brings together the perceptions of the people involved in these organizations and their major concerns.

This research was conducted in Maputo, Chimoio and Quelimane cities in Maputo, Manica and Zambezia provinces respectively. It is in these three provinces where the first associations of people living with HIV/AIDS PLWHA were located. This specific task was to observe the way associations interact in their respective offices and/or clinics. It also gave the opportunity to look at the ways they deal with their members including their common problems.

Along side this method the research also includes the combination *semi-structured, open-ended interviews*. *Semi structured interviews* were administered to the board members of local and international NGOs as well as government institutions. *Open -ended interviews* for members of the associations and *case studies* were also recorded from some people living with HIV/AIDS in the associations.

Participant observation during fieldwork was the principal method for data collection. In short, a *multimodal approach* was an effective strategy towards strengthening the sources' reliability.

Fieldwork and procedures

The first step of the fieldwork was to make arrangements with the umbrella institutions based in Maputo which directly deal with associations of PLWHA at national level. In this way, four institutions were first contacted:

1. Rensida *Rede Nacional de Pessoas Vivendo com SIDA*, an umbrella organization that is working with associations of PLWHA.
2. MONASO, 'Mozambican Network of AIDS Service Organization' that includes national and international NGOs dealing with HIV/AIDS issues.

3. CNCS, *Conselho Nacional de Combate ao SIDA*, 'National Council on the Fight against HIV/AIDS' is a governmental institution which coordinates all activities related to HIV/AIDS at all governmental, civil society and private sector levels.
4. Ministry of Health which supervises all issues related to public health including the HIV/AIDS pandemic.

This strategy enabled me to have a picture of what these associations have been doing in the context of HIV/AIDS in Mozambique on the one hand, and to make arrangement for later contact from there with the associations and others institutions targeted for this research, on the other hand.

After this step I came to the second step of *in-depth interviews*. In Maputo I interviewed a number of the governmental institutions such as Ministry of Health, Ministry of Woman and Coordination of Welfare, Hospital dia and CNCS. All these institutions were also contacted at provincial level. All interviews were taped for transcription.

In the process, I also dealt with NGOs both national and international. One or two officers from each of them were contacted. The selection was done according to the level of involvement in HIV/AIDS issues. From HIV associations, however, I interviewed two staff members, the president or the executive director or secretary, or both of them, depending on their availability. In the provinces five members of the same associations who were targeted responded as well to the requests. The number of National and international NGOs in each province varied from one province to another. The majority of them were contacted whenever they were referred to the author by others during our interviews.

It is important to observe that this study was possible only in the capital cities of the provinces for the simple reason that the districts do not have associations of people living with HIV.

In Maputo were in total 25 interviews with HIV-AIDS positive effective members of the associations including case histories of NGOs, national and international, and five governmental institutions. Similarly, in Quelimane two interviews were conducted with

HIV associations, ten HIV positive members belonging to both existent associations. Three International and three National NGOs were contacted as well as the three most important governmental institutions at provincial level: Health, Women and coordination of Welfare and CNCS National Council on the Fight against HIV/AIDS.

In Chimoio were contacted two associations made up of twelve members, six in each association. Two international and three national NGOs were contacted. The same governmental institutions contacted in Quelimane were also visited and contacted in Chimoio.

Given the nature of the study, it was not easy for some people to respond to the interviews for fear of discrimination and stigmatization. In Maputo, for example, in one of the support group I was asked to reveal my sero status – to determine whether I was like them, since this would make them comfortable during the interview. Skhosana confirms how difficult is to conduct study in this perspective. According to her, she found specific strategies in that moment to deal with her research (Skhosana: 2001)

In Manica province I was asked by two young people to be paid for having been interviewed. It has been a practice for some researchers to pay the interviewees. However I did not pay informants for information.

Special problems arose during the fieldwork in all studied provinces when some associations (i.e. members of the board) of HIV people were the ones who decided which people should be interviewed and which not. Without their mobilization it was not possible for me to find people for those interviews.

All in all, the fieldwork covered a period of three months. It should be acknowledged that all was done successfully but not without some obstructions. I quickly learned an important lesson that a researcher even in her own country should not assume that the interviews will be transparent and unproblematic. As a field worker I was, also able to learn more than the scope of the research itself. I was able to notice laughter, reprimand, correction through which I had to see how people living with HIV socialize or fail to socialize with others.

Constraints

Language or communication barrier was one of the difficulties I had in the field, but not a major one. In cities where most people speak Portuguese, I chose Portuguese as a language for communication. However, some HIV positive were more confident speaking in their native languages, I solved the problems through interpreters.

Photographs were taken to document some findings and they added support to the data collected. Verbal consent of participants was sought before photographs were taken. Some of the informants did not allow pictures, fearing that I could sell their images.

Ethical considerations

Given its delicacy, this research topic has a lot to do with informant's intimate life and privacy. Interviews were conducted in a careful manner, following the principles of respect and confidentiality according to the WITS University's statement of principles and the American Anthropological Association's statement of Ethical principles for Anthropology. I made our informants aware of the research's purpose, which is to seek and contribute to further improvement of the associations of PLWHV and their memberships and obtained verbal or implicit consent. In learning about others through active participation in all steps of my fieldwork, I learned for example, in this context of HIV, those who were suffering from it, I tried by all means to make them feel free and more comfortable despite their status. I also protected their identity as professionally required for an anthropologist researcher. In short, respect and confidentiality were the most important requirements considered during the fieldwork.

Structure of the work

In **Chapter I** of this work, a brief overview of the topic is outlined. The Introduction identifies also the scope of the study of PLWHA 'People Living with AIDS'. The concept of civil society and social movements are discussed. The principal techniques used in the research, are described.

Chapter II gives a broad picture of HIV/AIDS in Mozambique. After years of colonial rule, civil war, floods and famine, Mozambique is now considered one of the world's poorest countries with one of the highest HIV infection rates – 13.6% of 15-49 year olds are HIV positive. This chapter gives a picture of PLWHA organizations in fighting against HIV/AIDS and helping HIV people.

The literature review is the main concern of **Chapter III**. This section provides the sources cited throughout the work. It offers information on the range of other studies cited and how they influence this work. I include work of scientists in other disciplines, such as bio-medical, psychology, and culture. The literature cited in this section shows how HIV/AIDS issue is the concern of everybody and not just anthropologists.

Chapter IV is about presentation of the three provinces in study. The general idea of these provinces related to the location in the country as well as the population is given. Some socio- economic indicators are shown in the context of specificities of each provinces. Factors that would influence the prevalence of HIV/AIDS are presented. On the end there is presented the PLWA organizations in each province and a brief history of their creation and function.

Chapter V deals with the presentation and analysis of results. This results section contains the **data** collected during experimentation. It is the heart of this paper. In this section, much of the important information is in the form of translated interviews. Tables and graphs of characterization of members of the associations of PLWA are also given.

The **Conclusion VI** re-states clearly and concisely the key issues covered in each of the main points in the body of the text, and provide a concluding statement that integrates the ideas presented there.

CHAPTER 2- BACKGROUND INFORMATION ON HIV/AIDS IN MOZAMBIQUE

Country profile



Mozambique



Fig. 1 Map of Mozambique country
([http // www.worldpress.org/ profiles/ Mozambique](http://www.worldpress.org/profiles/Mozambique))

The population of this country is approximately 18 million people where more than 99% belong to indigenous ethnic groups. The ratio of men to women is 96 to 100. Forty-two percent of the population is under the age of 15. (INE: 2000)

Mozambique is considered one of the world's poorest countries, and all of the country's social indicators are well below sub-Saharan African averages. Mozambique's ten-year civil war reversed post independence improvements in basic services and had a major impact on mortality and morbidity, especially among children. Thirty to forty percent of Mozambique's children are chronically malnourished. Roughly 60 percent of the population still lack access to health services. The Mozambican government now allocates 8 percent of its current budget—about US\$2 per person per year—to the health sector. (INE: 2000)

During most of the civil war, the government was unable to exercise effective control outside of urban areas, many of which were cut off from the capital. An estimated 1 million Mozambicans perished during the civil war, 1.7 million took refuge in neighboring states, and several million more were internally displaced. In the third FRELIMO party congress in 1983, President Samora Machel conceded the failure of socialism and the need for major political and economic reforms.

In December 2004, Mozambique underwent a delicate transition as Joaquim Chissano stepped down after 18 years in office. His newly elected successor, Armando Emilio Guebuza, has promised to continue the sound economic policies that have encouraged foreign investment.

Part of the poor conditions in Mozambique is a heritage of Portuguese colonization, because under this regime, educational opportunities for black Mozambicans were limited, and 93% of that population was illiterate. In fact, most of today's political leaders were educated in missionary schools. After independence, the government placed a high priority on expanding education, which reduced the illiteracy rate to about two-thirds as

primary school enrollment increased. Unfortunately, in recent years school construction and teacher training enrollments have not kept up with population increases. With post-war enrollments reaching all-time highs, the quality of education has suffered. However this has improved after independence (Serra: 2000).

HIV/AIDS in Mozambique

HIV/AIDS is one of the greatest threats to the development of Mozambique, kills people in their productive and reproductive years. This pandemic has a responsibility to increase the vulnerability of the families associated with the increasing of numbers of orphans in the country. Health and education services are losing skilled staff, reducing the provision of these services.

According to the MISAU, Ministry of Health and the INE the epidemic situation of HIV/AIDS in Mozambique by province and by the three regions in 2002

Province of Mozambique	Prevalence %	Prevalence %/ Region
Niassa	11.1%	8.4% North region
Cabo Delgado	7.5%	
Nampula	8.1%	
Sofala	26%	16.7% Center region
Manica ³	19%	
Tete	14.2%	
Zambezia	12.5%	
Maputo city	17.3%	14.8% South region
Maputo province	17.4%	
Gaza	16.4%	
Inhambane	8.6%	
Mozambique	13.4%	
Mozambique actually	16.2%	

Table 1 HIV Prevalence by Province. Source: MISAU: 2002 and 2005

According to MISAU pointed that in 2001 about 56.600 adult people have died by AIDS
Concerning the life expectation according to the projection, in 1999 it was 43 years; 2004 46.4 years and in 2010 could be 50.3 years without AIDS. However the life expectation

³ The provinces in red are that in study

with AIDS in Mozambique at the same periods was 41 years; 38 1 years and will be 35.9 years with AIDS, respectively. (MISAU: 2005).

For the surprise of Mozambican the recent data of Ministry of Heath indicate that the current national prevalence 2005 is 16.2 %. Half of the people living with HIV/AIDS (PLWHA) in Mozambique are between the ages of 15 and 29. Girls and women are at especially high risk and are being infected at a ratio of two to one over men. In 2004 we had 470,000 orphans due to HIV/AIDS in Mozambique. Currently, we have more than this figure, which will increase to over one million orphans by 2010. (MISAU: 2005). Extreme poverty, urban and cross-border migration, unequal distribution of power between men and women, stigma, and low literacy levels fuel the HIV/AIDS epidemic.

The first AIDS case was reported in Mozambique in 1986. The country's HIV prevalence rate is lower than the rates of neighboring Zimbabwe, Zambia and Malawi, largely due to the isolating effects of the civil war.

The scale and future impact of HIV/AIDS in Mozambique can only be understood by examining it in relation to its young population. Youth, aged 10-24, comprise 34% of Mozambique's population, and youth aged 15-24 account for 60% of new HIV infections in a country estimated to have a HIV prevalence rate of over 12% (MISAU:2005) .

Although the isolating effects of a ten-year civil war kept the HIV prevalence rate in Mozambique lower than the rates in neighboring countries, it is still one of the nine countries in Africa hardest hit by the epidemic: Given the increasing number of people suffering from HIV/AIDS the Mozambican government has approved antiretroviral therapy (ATR) and diagnostics policy in the country. But the costs due to the rising number of persons living with HI/AIDS will overwhelm an already existent health care budget. Prevention activities focused on young people, the mobile population, better quality and coverage of voluntary counseling and testing services. The actual cost of ARV treatment per patient is 250 USD per year what means that the government has to expend too much money only for this matter while malaria tuberculosis, cholera continue to kill more than AIDS (CNCS: 2005)

In short, Mozambique is a country where people have seen all. The Mozambique Liberation Front, or Frelimo, formed in 1962 by Eduardo Mondlane, Frelimo sought to completely liberate the country from Portuguese rule. The war lasted over 10 years, effectively ending in 1974 when the fascist regime was overthrown. The independent Republic of Mozambique was proclaimed on 25 June 1975:

Then troubles really began. The drought and famine of 1983 also brought the country to its knees. In January 2001, floods killed about 700 people, left half a million homeless and devastated the economy. Some of the flooded areas - and many others besides - were then hit by a drought the following year. The economy remained crippled by debt, with annual payments almost twice the public health budget. Above and overall the country is fighting against HIV/AIDS today.

NGOs and HIV/AIDS in Mozambique

The NGO sector in most countries like Mozambique led the early responses to HIV/AIDS issue. There are many different typologies and classifications of these NGOs. However we can distinguish two: national and foreigner NGOs that specifically dealing with AIDS called by AIDS services. Normally these organizations are members of MONASO and RENSIDA national umbrellas of organizations dealing with HIV/AIDS and of PLWA respectively. Since the end of decade 80 local NGOs of PLWA started emerging and integrating these two umbrellas.

These organizations in general focus their activities mainly on the following areas:

- Prevention of sexually transmitted diseases and of HIV/AIDS transmission among young people through school awareness programmes;
- Fight against discrimination, stigmatisation and marginalisation of people affected by and infected with HIV/AIDS;
- Support of families caring for relatives living with HIV/AIDS;
- Care for children orphaned by HIV/AIDS.

- Advocacy for ARV treatment
- Few of them in partnership with the government provide ARV treatment

The increasing number of PLWA members enlarged the “HIV community” that wanted to organize themselves. Similarly, the increasing disclosure of HIV- positive status has led to the formation a national network of PLWHA, as already indicated in the introduction, which works in partnership with other organizations and the government. The RENSIDA (National Network of People Living with HIV/AIDS was created in 2000.

In this Network are included PLWA but mostly who are member of HIV/AIDS associations. The most important aim of this National network is to stimulate the formation of self-help groups of local People Living with HIV/AIDS, to coordinate and support their activities, and to help bring them together in one voice. This network for PLWHA receives financial support from SAT, UNICEF, Action Aid and ONUSIDA (interview with secretary of Rensida ,2004: Maputo)

The association known as *Kindlimuka* ‘wake up’ in the local Ronga language is the oldest of the PLWHA organizations in Mozambique, founded in 1996. Based on Kindlimuka’s experience, thirteen other associations of PLWHA have been established in others provinces. The formation of these associations is behind National and Inetrnational NGOs as well as governmental institutions such as services of blood and GATVs. (services of counseling and voluntary test)

These associations have as main tasks:

- Providing counseling, home -based care and inc ome generation activities including the production and sale of clothing and material for construction.
- Organizing education on how to prevent HIV/AIDS for young people aged 13-18 years in schools. Testimonials by association members on their sero-status have become an effective tool used to reduce stigma and to increase awareness.

- Identifying vulnerable children and families caring for orphans, with involvement of community leaders.

RENSIDA is an umbrella organization. It is a Non-Governmental Organization, which integrates all organizations of People Living with HIV/AIDS in Mozambique. Activities implemented by RENSIDA with the UNICEF complement each other. UNICEF has been supporting institutional capacity building of RENSIDA through technical advice, training, and the provision of material and equipment. RENSIDA developed a national strategic plan and operational plans of the associations in 11 provinces for 2004. In addition, UNICEF has been supporting community monitoring projects for orphaned and vulnerable Children through RENSIDA in fifteen districts in Gaza (Kuvumbana), Manica, Sofala, Tete and Zambézia provinces

CHAPTER 3 - LITERATURE REVIEW

HIV/AIDS as a social phenomenon

Today, as in the past, those who write about the issue of HIV/AIDS emphasize the role of people living with HIV as infectors rather than those who are infected to such an extent that this view is widely accepted as "common sense." In public health initiatives, the "public" appears not to be concerned about how to help these people who contracted HIV to live a better life of stigma, rejection and marginalization, and also help them not to disseminate or transmit the virus to others – innocent people and children considered to be potentially innocent victims of AIDS, at the expense of others like prostitutes. But, in so doing, writers promote oppression of HIV positive people and impede the struggle against HIV.

The first cases of HIV/AIDS in the world were associated to the homosexual people and drug users so people in the heterosexual life were not concerned about this disease.

Today many people blame prostitutes or sex workers. Generally, women and men working in the sex trade have been considered as vectors for transmission rather than persons who, for many reasons, including legal reasons, are vulnerable to contracting HIV. But most recently, the evidences show that every one is susceptible to be HIV positive independently of their sexual orientation. Related to HIV/AIDS indicators in Africa, are handicapped by inadequate means of confirming diagnosis, on the other hand the high sickness rates contribute in a large way to obscuring the true prevalence of HIV/AIDS in many African countries (Agadzi, 1989: 92). HIV/AIDS cannot be seen anymore as only a bio-medical disease. "Specific social and cultural patterns such as the sexual networks, the availability of needles, the political and economic power relationship of prostitution, the nature of transport routes areas of high prevalence are factors showing the social face of this disease" (Altman, 1994).

As Altman remarks that no illness in human history has generated so many meetings, so many scientific publications, nor so much political rhetoric and government response Altman, 1994:2) as HIV/AIDS. In fact, a number of articles trace the history of

HIV/AIDS (Altman, 1994; Macks, 1987; McAdam, 1996; Agadzi, 1989; Corr, 1994; Cad & E, 2002). Though different resources have been consulted in the frame of this research, this work, however, has heavily drawn on the research conducted by Altman's *Power and Community: Organizational and Cultural Responses to AIDS*, 1994 that discusses various HIV/AIDS organizations. It shows how other forms of responses to HIV did not successfully help those who live with the virus and how, most striking of all has been the response from those most affected by the epidemic itself. It strengthens the idea that without strong community-based responses the best meaning of public health systems will fail to deal with the crisis of AIDS. For Altman "one of the major goals of the community-based movement has been to slowly drag public officials to recognition of the multi-faceted needs of an appropriate HIV/AIDS strategy.

HIV/AIDS and vulnerability of poor people

Altman recognizes that the HIV spread and its social consequences are closely linked to the dislocations of economic and social 'development' and, in West, to the growth of particular sub-cultures and regimes of sexuality. In other words, a single approach the study of this pandemic cannot help; it needs to be approached from various angles, including cultural and economic aspects. According to PNUD (2004) 39.4 million people are estimated to be living with HIV 25.4 millions can be find in Sub Saharan Africa. The increasing number of people with AIDS in Africa mainly in Southern Africa, for example, allows us to associate this disease with poverty. Obviously, the people of this region are most frequently infected because of their life conditions (Altman: 1994).

Lancet (2004) in Preventing HIV/AIDS through poverty reduction remarks that the association of poverty with increased HIV prevalence does not necessarily indicate a causal relation. But for him, explanations have been offered at several levels as to how poverty may increase susceptibility to HIV/AIDS. He has also argued that poverty increases biological susceptibility to HIV/AIDS in the same way it does many other infectious diseases. When he refers to the malnutrition, parasitosis, and lack of access to health care among the poor, suggests that these factors undermine the integrity and immunity, and increase the likelihood of having other

untreated sexually transmitted infections. All of these influences can increase susceptibility to HIV infection and progression.

Of significance in this debate is also the fact that poverty is not alone in its destruction. It is also often associated with lack of education, and illiteracy can mean that messages regarding risk and prevention are inaccessible. These authors continue to argue that even with knowledge of the risks; the cost of prevention may be prohibitively high because many poor people are unable to afford condoms. Poverty also restricts people's choices and leaves few options but to undertake high risk behaviors. It is in this context that in Lancet (2004) also identified poverty-driven labor migration and commercial sex work as activities likely to increase HIV infection.

Thus, poverty is one important factor in increasing susceptibility to HIV/AIDS, and facilitating its spread. HIV/AIDS also increases poverty, at all levels from individual to nation, through its impact on working age populations. The morbidity and mortality among this age group affects household incomes, and is a major challenge to the ability to deliver services such as education. It is important to recognize, however, that there are many other influences besides poverty acting to facilitate the spread of HIV/AIDS. Income and gender inequalities are likely to be as important as absolute poverty, as shown by the high prevalence of HIV/AIDS in countries with large inequalities. Other challenges include finding the political will to combat the epidemic, and the stigma associated with HIV/AIDS.

With respect to this debate two conclusions to be drawn from the above observations. First, since poverty plays a role in creating an environment in which individuals are particularly susceptible and vulnerable to HIV/AIDS, poverty reduction will undoubtedly be at the core of a sustainable solution to HIV/AIDS. Therefore, investment in equitable poverty reduction efforts must continue, even in the face of other pressing needs. Second, since poverty is clearly not the only factor contributing to the spread of HIV/AIDS, there is no excuse for taking a fatalistic attitude to the epidemic, in which little can be done until some utopian poverty-free ideal has been achieved. We can concur with Lancet, and others that social factors such as poverty, gender inequality and illiteracy

are closely related to HIV/AIDS increase and need to be studied deeply, reduced if we have to succeed in our fight against HIV in Africa and Mozambique in particular.

There are more studies relating HIV/AIDS to poverty specifically on household of developing countries. Desmond and Gow advance the view that the capacity of vulnerable household and communities to respond to the economic, social, and health impact of HIV/AIDS on their households are weakened ever day due to extreme poverty. women and children are the most seriously affected “ that is why anthropology has the methodological tools to study the social experiences of those who are afflicted by this disease while simultaneously keeping the humanity of those who are infected in the professional discourse on AIDS” (Desmond & Gow, 2002:19).

HIV/AIDS pandemic as already stated above required the involvement of community-based organizations because other groups which existed before these did not include those most affected by the epidemic. In Latin America people place stress on the concept of civil society and the need to strengthen it. In this work the stress is on the civil society which we believe can help organizations of people living with HI/AIDS such as PLWHA. Like Altman, we believe that the importance of intellectuals in the largest sense may help communities make sense of meanings of AIDS. Hence the emphasis on anthropological intervention in this research which puts high demands on social and cultural aspects of HIV/AIDS.

Countrywide organizations of PLWA

National Networks of People Living with HIV/AIDS worldwide are becoming more and more powerful acting on behalf of all people living with HIV/AIDS. The oldest national AIDS network organization in the world was found in the USA, in 1983. According to NAPWA, too little attention has been paid to the very real issue of meeting the prevention needs of people living with HIV/AIDS. The best strategies for preventing new HIV/AIDS infections should engage people with HIV/AIDS as partners, but it is also important to consider that people living with HIV/AIDS are extremely heterogeneous, and programs need to address the different needs of such a diverse group: Race, gender, sexual orientation, age, language, geography etc.

People Living with HIV/AIDS in the world are been organized themselves as a way to respond the epidemic rather than being blamed for the epidemic or regarded simply as its unfortunate victims. So HIV positive people have been valued as one of the society's most important assets in coping with the effects of the pandemic and preventing its further spread.

The global Network of PLWHA is a world network for and by people with HIV/AIDS. It is based in Amsterdam, Netherlands, and has a board of 12 members representing the various international regions. The overall aim of GNP is to work towards improving the quality of life of people living with HIV/AIDS. This can be achieved through the capacity building of people with HIV/AIDS.

According to Williams (1995), PLWHA associations in general, have the following objectives: (1) psychological care, (2) emotional support, (3) medical treatment and nursing, (4) information, (5) material assistance, (6) acceptance and non-discrimination. As mentioned above, the association's primary objective is to support people living with HIV/AIDS and their family members. It could be in terms of moral or economic support. Some of them provide community and home care assistance. Their membership is mostly impoverished people, thus limiting their capacity and effectiveness in advocacy. This also reflects the existing social stigmatization against them from the moment they reveal to be HIV positive or AIDS patient. This is a real situation in Mozambique. In different parts of the world, for instance in Uganda where HIV/AIDS awareness is high and greatly supported by the civil society, there are national networks of this kind of associations.

The examples of Uganda and South Africa

Organizations of PLWHA worldwide enface the problem of discrimination and stigma, but given the increasing number of infected people and this kind of associations they are fighting these issues with a relative success. This has proved true in Uganda through the TASO Organization of People Living with HIV/AIDS and NEPWA National Association of People Living with HIV/AIDS in South Africa where they have been extremely important in shaping their society's response to HIV/AIDS.

In fact, Uganda's response to HIV/AIDS has been comprehensive therefore is seen as a model for the rest of Sub-Saharan Africa. Since 1992 HIV prevalence in Uganda has dropped by more than 50%. The involvement of government institutions, the civil society as well as numerous community led initiatives could be the most important factors for decreasing HIV/AIDS in this country.

(www.cdc.gov/nchstp/od/gap/country/uganda.htm)

Organizations like TASO (The AIDS Support Organization) and Phill Lutaya initiatives strive to put a "*human face to HIV/AIDS*". So ordinary citizens associated AIDS with real people then their own risk perception increased and turn were more receptive to campaigns for safer sex. (www.aidsugand.org/pdf/role-of_vct.pdf)

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Authors like Fieldman and Carter add that successful battle against HIV/AIDS in Uganda can be also associated to the government policy strategy consisted in empowering women giving them the voice in first person. On the other the encouragement to bring out people in good status to talk about their sero positive status was helpful to combat the stigma. (Fielman & Carter, 2003).

NAPWA's international programs works to combat the HIV/AIDS epidemic by advocating for the needs of people living with HIV/AIDS and promoting the active engagement and leadership of PLWHA established partnership with other parts in the world, specially in Africa and the Caribbean countries. There are many National networks of PLWHA in the world, for example, PLWA in Australia which advocates on

behalf of people living with HIV/AIDS. This umbrella works with government researchers and pharmaceutical services. (<http://www.napwa.org.au>)

In Africa, for instance, we can take the cases of South Africa and Uganda, whereby such national networks seem to be well established. The success of South African NAPWA movement had to do with the strong experience of *civil society*. This has been able to draw on the organizational and advocacy experience of the anti-apartheid movement as well as the gay and lesbian movement. It attracted educated individuals and professionals as well as poor and marginalized people (Centre for Policy Studies, 2001: 36).

NAPWA (National association of people with AIDS) in South Africa is a non-discriminatory organization, formed in 1994 seeking to promote a safe and secure involvement that guarantees the basic Human Rights and dignity for those who are HIV positive. This organization strives to provide care and support to the membership as well as to mobilize and organize lobby and advocacy. NAPWA is, moreover, an organization whose membership is open to all people living with HIV/AIDS. Its most important programs are: mobilization, advocacy and lobbying, partnership and collaboration, gender program, organizational development and counseling and support (www.napwa.org.za).

The same structure can be found in Uganda where, because of the seriousness of the situation there, civil society, together with government, labor and business had to be strongly involved in HIV/AIDS related matters. There is an umbrella of people living with HIV/AIDS called TASO, and the 'AIDS services organization'.

The impact of these organizations even though some important achievements is still relatively limited, considering the rapid spread of the disease; Goss and Adam-Smith (1995) argue, however, that pressure groups formed by PLWHA were being represented in organizations and trying to articulate an appropriate response.

One of the most important lessons Africa has learnt in the fight against HIV/AIDS pandemic is that of '*multisectoral approach*⁴', which has proved to be a condition for successful battle. It means that all stakeholders namely government, private sector, the civil society and the media at all levels '*must come together to find ways to work against the common foe*' (Thornton 2003: 23).

HIV/AIDS and Gender Issues

"HIV/AIDS has a female face"

Worldwide in 2004 there were about 37.2 millions adult people living with HIV, of them 17.6 were women and 2.2 children (UNAIDS: 2004).

In Africa the number of women infected with HIV outnumbers infected men. Twelve point two million African women are living with HIV/AIDS as compared with 10.1 million men young African women between 15-19 are four to six times more infected than young men of the same age (Tallis, 2000:26).

Rachel Royce in Vallaers, in her article about *Awareness Is Not Enough: Gender in the HIV/AIDS Pandemic in Africa*, gives considerable ideas on the impact of gender relation and HIV/AIDS. She remarks that HIV has been called a "biologically sexist" virus by scientists, because women are in much greater danger of contracting the disease during sexual intercourse than the man. In the absence of sexually transmitted infections, a man with HIV/AIDS has an average chance of one in 500 of passing the virus to a woman in a single act of unprotected vaginal intercourse. The odds of woman-to-man transmission in the same situation are about one in 1000.

Women under the age of twenty are more likely to contract HIV because an immature genital tract has fewer layers of mucous membrane, increasing the chances that the virus enters the bloodstream. In the presence of lesions in the genital tract, the risk of contracting HIV increases up to sevenfold (Rachel Royce :2005).

⁴ This is the Ugandan approach, developed in the early 1990s.

But Women are not only at a biological disadvantage, but at a social disadvantage as well. World Health Organization (WHO), "Fact Sheet No. 242," June 2000 mentioned that "the second-class status of women in economic, social and civic life has fuelled the pandemic in much of the world." In addition, as Lesley Doyal, a Health Studies expert of Africa, pointed out that "women cannot use condoms in the way most government programs recommend. Instead they must persuade men to do so, and this can be an extremely difficult task." She further argues that in traditional African relations, women are not expected to discuss or make decisions about sexuality. Women do not have control over condom use, they also have little control over their husband's sexual practices. Women are placed at a high risk of contracting the virus, not from their own behavior, but from the behavior of men over whom they have little control.

It looks like women are victims of a patriarchal system that robs them of the freedom over their own bodies.

It is once more clear how women are disadvantaged in protecting themselves.

Following Rachel Royce in Vallaes (2005) in a culture that places such high value on family life, and in which family size is an issue of gaining status and respect in the community, it may very well be futile to urge married couples to use condoms. In this case, not using a condom is in the best interest of the woman as well, because "in many societies, motherhood represents the only route to status, identity and personhood, and ultimately security and support in old age. As one can see, conception cannot be combined with safe sex, and most Africans want large families. Not only is the joy of having children enough reason to disregard the advice of using a condom, but there are other cultural and economic factors as well.

Given that the configuration of gender relation in Africa is associated with sexual behavior and economic security, this relation not only underlies women's particular vulnerability but also inhibit women's security and their families (Beylies: 2000). It is also believed that it is "Only when gender inequality becomes a central part of HIV/AIDS programs can we then hope to make an impact on the course of the epidemic" (Tallis, 2000: 5) So, in addition to biological and social factors, the economic situation of women in Africa also contributes to their increased endangerment of contracting HIV.

The study of rural household in Uganda has revealed that more women are dead than men. The same author remarks, however, that in countries where the majority of infected people are men, women living with HIV/AIDS are often invisible. This means that their needs are not articulated or if they are, they are not heard and not addressed ((Tallis, V., 2000: 61).

In most African countries it is women and men in the midst of their productive and reproductive lives who are most likely to become infected by HIV and die. However, given a typical age difference between partners of five to ten years, females tend to be infected at younger age. Women are infected at an earlier age. Given more rapid disease progression with age, husbands often die more quickly, leaving more widows. (Baylies: 2000:10-12).

Mozambique would not be an exception this gender issue UNAIDS also confirm that the number of women living with HIV/AIDS is growing, and women experience socio economic inequalities and discrimination, particularly aggravated with the deterioration of socio economic conditions in the country given the adoption of market economy, the makes the life waste for women concerning to access health and social services.

www.info.usaid.gov/pop-health.

African men easily forget the fact that performing sexually with many partners place them at risk of HIV/AIDS infection. This in turn has impacts on women who have little power and control in sexual interactions. Such power dynamics in heterosexual relationships raise issues in relation to HIV/AIDS that have been addressed in other

contexts, for example – sexuality, relationships access to health care, women's burden/role in health care and reproductive rights. (Tallis, 2000:60).

This is an indication of how this work cannot achieve more without addressing the issue of gender roles. It is in this regard that the International Community of Women Living With HIV/AIDS (ICW) was created in 1992 at the international AIDS conference in Amsterdam. ICW was created with a purpose to share concerns about the lack of support and dearth of information available to HIV positive women worldwide of Women Living with HIV/AIDS (WLWA) through challenging discrimination and stigma with self empowerment and self-sufficiency, dissemination of information, skill-building training research and advocacy (Artman, 1989: 25).

To return to the importance of our research regarding HIV/AIDS, let us finally remark that in discussing the issue of HIV/AIDS, safe sex and risk reduction, there is a need to take into account the way in which high risk sexual behaviour is embedded in systems of socio-cultural, economic and political exchange, particularly those systems of exchange, which typify gendered power relations between men and women. But all in all, we are enriched through this literature review to understand that HIV/AIDS needs a multiple approach rather than just a single approach

CHAPTER 4 - GENERAL OVERVIEW OF THE THREE PROVINCES IN STUDY

Introduction

The specific nature of AIDS epidemic varies from place to place, depending on historical circumstance, cultural context and contemporary political economy (...) disease is a social event, which expresses the central realities of the society in which it occurs''.(Bujura & Baylie, 2000: 25)

In the absence of a straightforward medical cure, understanding of the spread of HIV/AIDS and advice about how to intervene to limit its spread, should be largely social scientific in nature. Therefore, Social Sciences should provide the main components of the relevant knowledge-base. The very considerable regional differences of social phenomena require a particular mobilization of social science knowledge about each particular society or regional grouping of like societies.

Following this assumption this section focuses on similarities and differences in the three provinces and explains the various factors that may be behind them, in order to trace specific characteristics in the context of HIV/AIDS and its associations. It is important to speak of some economic and social factors related to HIV before speaking about HIV itself in each province. It has been observed, for example, that a high risk of HIV among people, especially adolescent is concentrated among the most socio-economically disadvantaged. There is, for example, a relationship between poverty and HIV/AIDS which includes the spatial and socio-economic distribution of HIV infection in Mozambique. That is why we will discuss HIV in each province by including social factors such as:

- geographical location;

- population mobility; and
- relevant socio cultural aspects that may be behind the HIV community in each province.

These general considerations will be followed by the story of HIV/AIDS associations in each of province.

Talking about HIV/AIDS and its associations which Altman (1994) prefers to call the Community-based organizations (CBOs), it requires first the understanding of what the term ‘community’ is all about because community is at the center of every association.

According to Altman (1994) the term ‘community’ is usually applied to a group of people defined by certain boundaries, such as race, ethnicity, religion or profession. In other words, community is defined in geographical terms; indeed, many of the central works in ‘community studies assume a geographical base to ‘community’. Others have given it a spiritual meaning, as in M.Scott Peck’s assertion that this term should be restricted to a group of individuals who have learned how to communicate honestly with each other, whose relationships go deeper than their masks of composure, and who have developed some significant commitment to ‘rejoice together, mourn together’ and ‘to delight in each other, make others’ conditions our own’ (Altman, 1994:7-8).

In light of the above perception, the author also agree with Peck’s definition of community as a group of individuals who have learned how to communicate honestly with each other and whose relationships go deeper than their masks of composure, and who have developed some significant commitment to ‘rejoice together, mourn together’ and ‘to delight in each other, make others’ conditions our own’. The author also believe that what makes these associations succeed in Mozambique is the fact that people living the same geographical space have the same culture (or belief system) and history to which they add the same sorrow imposed on them by the pandemic. All these things combined can help them to support one another and help them chart the best way forward.

But the question which still persists is what does being a member of a HIV Community mean?

Without a doubt each of these activities represents an important element that makes PLWHAs comprehensive HIV communities. If we go from the predicament that the best thing among people is the one which is the most beneficial for mankind, and that good members of the community are the ones who are productive and dynamic or the ones who care for the welfare of the Community, it is easy to deduce that PLWHAs are part of the HIV community seem to be involved more than the extent to which they personally benefit from the HIV people. They contribute for the benefit of others not looking for a reward. The above arguments give to the word community a broader context which includes both those who live with the virus and the organizations looking after them.

Maputo province

Geographical situation

Mozambique is divided into three geographical regions: south, centre and north. Maputo and another two provinces (Gaza and Inhambane) constitute the south regions.

This province has as its board countries South Africa and Swaziland.

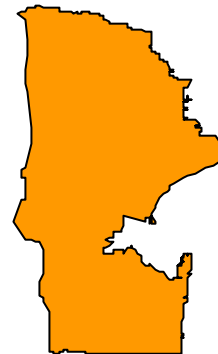


Fig.2 Map of Maputo Province

Population

In terms of population according to INE: 1997 there were 2.700 million inhabitants and the majority was concentrated in Maputo city, with about 1.800 million inhabitants. Maputo has a strong relationship with South Africa through mine labour migration since 19th century. Many people in Mozambique continue to cross the border legally or illegally looking for job in the mine areas or elsewhere like in the farms.

The International Organization of Migration (IOM, 2004) has shown that there is a straight relationship between HIV/AIDS and migration. The HIV infection is frequent in men who work far from home and live in single hostels like miners and others workers. For example there are many mine workers returning home when they are already sick-with AIDS. The risk of infecting others is in sexual relations with their partners while they are infected.

Beside all this, Maputo is part of an important corridor that links this city to Johannesburg, there are so many important roads that link this city to other country in the region such as Swaziland and South Africa from Durban. The same way that the mosquito transmits malaria and the dirty water cholera, HIV is transmitted by contact of people by travelling.

A quick look the city of Maputo clearly shows that in Maputo there is

- a confluence of people from different parts of others province who come to look for jobs or better conditions of lives;
- people from others countries embassies and international agencies are located there;
- there are the most important institutions such as universities, media, trade and enterprises;
- Important sectors of civil society are concentrated here;
- UN agencies and others international organizations, donors and most important meetings and debates about this issue are also held in this city;
- a variety of mass media that help to spread information in the different communities are also found in this city.

These aspects put Maputo in advantageous position over other provinces.

HIV/AIDS ASSOCIATIONS

By HIV/AIDS associations here the author mean the local Aids initiatives which are non-profit organizations dedicated to promoting HIV/AIDS awareness in Mozambique by scaling up nation-wide prevention efforts and improving the lives of persons infected with or affected by HIV/AIDS. Kindlimuka was founded by those who were receiving counselling from AMODEFA. Kindlimuka was created around 1997 in Maputo city. AMODEFA is behind the creation of this association and that is why the members of this association use to say that *AMODEFA* is 'our father'. The first years of its existence the association used the premises of AMODEFA. By that time AMODEFA was working on programs of family planning, giving counsel to couples about issues of reproductive health. The most important part of this association is formed by nurses and other health workers. After some time, it was able to detect people with HIV problems and started to give counselling in this matter also. In 2000 the number of associations increased in Maputo due to the increasing number of infected people who, in turn, contributed to the creation GATVs (Gabinete de Aconselhamento e Testagem Voluntaria) what means Services of Counseling and Voluntary Testing such as *Thinena* and *Kuyakana kudumba*.

In addition, there are many organizations working with people living with HIV/AIDS. Examples of these are *FDC*, *Muleide*, *Kulima*, *Forum Mulher*, *AMME* and many others. These organizations work with or for PLWHA in different parts of Maputo and other provinces providing specific programmes for the Mozambican community. FDC has a specific programme *Kulhuvuka* along Maputo corridor in south region working with widows and giving financial assistance and civic education to infected people while *Muleide Kulima* and *Forum Mulher AMODEFA* are working in partnership with the international institutions and health services in care based home assistance to PLWA..In very recent years *Vidas positivas* 'Positive lives' was created. This NGO's primary aim is to providing counselling to HIV positive people. This organization tries to implement some strategies developed in South Africa. *Soul City Agency* in South Africa supports its actions. *Soul City*, is a South Africa NGO that was established in 1992 to harness the power of mass media and promote health and development in South Africa

and beyond is actually achieving its dreams. Its TV programmes or movies about HIV/AIDS are now implemented in Mozambique to help people know how to handle HIV issues.

Unlike the other provinces, PLWHA associations in Maputo have the possibility to negotiate the implementation of different programs thanks to the direct intervention government departments and other facilities. In short, the dynamic of HIV people associations in Maputo are privileged because the central services of government are based in Maputo as well as the others international institutions including the donors.

Manica province

Geographical situation

Manica province is situated in the central region of Mozambique. This region is composed by three provinces (*Sofala, Tete and Zambezia*). Manica has Zimbabwe as its neighbour.

Population

The population in this province is about 1900.000 of which a major part is concentrated in Chimoio (INE: 1997).

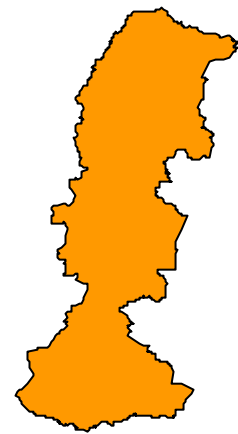


Fig.3 Map of Manica

This province was one of those most damaged by the civil war which lasted for some decades. During this war many people ran away from this province and went to other countries including Zimbabwe as refugees. During that time Zimbabwe was considered as one of the most affected countries by HIV/AIDS in Africa. It is often believed that the return of these immigrants (already infected by HIV in the neighbouring counties) to their own country after war also contributed to the increase or spread of HIV in the province or the country by large.

Besides this war, many socio-economic infrastructures in this country were also destroyed. The local government is still struggling to rebuild these infrastructures. Nevertheless, the recent political and economic crises in Zimbabwe have brought many

white framers from this country to Maputo and who have been exploring the land in this province. That is why Manica is seeing considerable improvement in terms of agriculture and trade these days. The infrastructures such as roads are also developing.

Similarly in Maputo there is in this region an important corridor created in 1990 as a way to strength the linkage between Mozambique and Zimbabwe. The corridor is from Port of Beira (Sofala) to Zimbabwe crossing Chimoio in Manica. This corridor brought large movements of people and goods from each country to another. This corridor, though economically important, has an impact on the dissemination of HIV/AIDS. The districts along this corridor (Beira, Dondo, Nhamatanda, Gondola, Chimoio, Sussundenga and Manica) are seriously affected by AIDS. The highest prevalence of HIV/AIDS in Mozambique is registered in this region with 26%, following by the south region with 19% and 9% in the north region (INE: 2004). The most apparent cause for highest level of HIV/AIDS prevalence in this province is justified by the immigration. Studies conducted by CEP⁵ also confirm that the internal mobility of people a long side this corridor has contributed seriously to the spread HIV/AIDS in Mozambique, in general, and in this region, in particular.

The HIV/AIDS Associations

Rudo kubatana is the first association that was created in this province since 1997. The province was the first one to become aware of the wide spread of this disease as it had noticed many people dying of AIDS by the end of 90s in Manica and more particularly in Chimoio. The return of displaced people from neighbouring countries was the most important reason. *Rudo Kubatana* in the first years of it existence was an important association aggregating many people with HIV/AIDS in Chimoio.

The thing that struck the most the author's mind here is the courage of people in this association in breaking silence about their HIV status (more details in chapter IV). At

⁵ CEP Centro the Estudos da Populacao (centre of population studies) belongs Eduardo Mondlane University

national level actions developed by this association became soon remarkable. Many of its activities gave this association the great reliability. Zimbabwean associations remained the role model of *Rudo Kubatana*. People learned quickly how to organise their association. They learned from what they saw happening in Zimbabwe as this country already had more experience in matters relating to HIV/AIDS as far as the 1980s.

Besides, Guinguirirai was founded in 2000 though its activities already existed since 1999. What is peculiar to Guinguirirai is the fact that emerged out of *Kubatsirane*, an ecumenical religious NGO. Among other activities *Kubatsirane* was working with PLWHA and in 2000 this organization decided to become autonomous. Thus it became autonomous even though it still remains part of *Kubatsirane*. It attends *Kubatsirane*'s meetings and gives advices on a number of issues. They still hold in common some concerns although they blocked out from each other. (Report given by Sister Rosa, coordinator of Guinguirirai, Chimoio: 2004)

GATVs in Manica started in 2001 as well as in many others provinces. In Maputo there is one support group as well as in Chimoio, Manica and Gondola districts. According to the provincial coordinator of Nucleo Provincial do Combate ao HIV/AIDS these three-support groups are preparing to form one association. The dynamic of the PLWHA in Manica complains about the financial resources to develop its activities as Manica people do not have many local donors to support their activities.

Zambezia province

Geographical situation

Zambezia province is part of the central region of the country. It has Quelimane as its capital city.

Population

Zambezia is the second biggest province and the second most populated with about three million of inhabitants (INE: 1997). Like

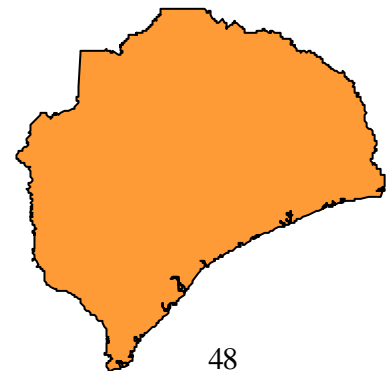


Fig. 4 Map of Zambezia

others capitals Quelimane also absorbs more than 1/3 of the provinces entire population that is estimated to be 1000 people (INE: 1997).

This province has Malawi as the country border. Like Manica province, Zambezia during the civil war saw many people migrating to Malawi as refugees. According to the data, the most refugee people of Mozambique during this war were based in Malawi (PNUD, 1996).

The linkage between Southern and Northern Mozambique is through the Zambezi River. To cross the country through this river is not easy due to the bad state that the bridges and roads in that part of the country. As result, many drivers prefer to make the turn around the river thus taking the route of north region via Malawi. Travelling by air is the fastest means of transport, but it is obvious that this is not given to the ordinary people without enough money. Despite the fact that the government is making efforts to rebuild the bridge, it is a fact that the Zambezia province remains is isolated from rest of the country. Maybe this isolation has for the time being preserved this province from high risk of conducting HIV/AIDS.

The HIV/AIDS associations

PLWHA associations in Zambezia like in Manica are not strong. PLWHA in Quelimane city has two branches: *Associacao Esperanca*, association Hope, and *Kewa*. *Associacao Esperanca* was created in 1997 and *kewa* in 2001. *Associacao Esperanca* has its origins in the provincial hospital. It is reported that this association started as result of blood tests. The increasing number of HIV people in Mozambique pushed the Blood services in this particular hospital to check all the donors of blood. Those found with HIV+ results were advised by nurses to share their burden together. From this mutual encouragement came the idea of starting an association. In 2000 other members of *Associacao Esperanca* decided to create a new branch, *Kewa*. This association is represented by a woman. *Kewa* is dynamic. It tries to extend its activities to other districts or provinces such as Mocuba, *Pebane* and *Maganja da Costa*. In terms of financial support, the PLWHA here get some support from the international NGO such as Action Aid, Save the Children and UNICEF.

“Empowerment” is the most important term to remember from PLWHA. It differs from traditional patriarchal benefactor strategies. PLWHA does not attempt to treat the HIV people as subjects; it emphasizes their participation and maintains the interaction between them, which we encourage here.

Conclusion

To conclude this chapter, the author first remarks that this study of social factors has reinforced our understanding of HIV/AIDS in these three provinces. We need, to remind ourselves that the organizations of PLWHAs need to shift their approach towards HIV. These organizations also have to approach the matter of this pandemic in different perspective. More efforts still need to be put in.

From this brief presentation of HIV overview of these three provinces, the author observed that there are several socio cultural factors that can influence drastically the dynamics of HIV/AIDS association. However two important aspects could be considered. For instance Maputo, the capital, presents more organizations working in HIV/AIDS, as well as, associations of people living with HIV/AIDS, while in Manica the active organizations could be explained by the fact of this province being close to Zimbabwe and learns from this country’s positive experience in this matter.

As a new phenomenon, HIV is a social event. At the same time, it demonstrates many unique features. This means that its impact on community life may be very different from one place to another. This section has shown that HIV/AIDS associations are capable of creating communities that not only facilitate connections between people but also provide supports for their members. Thus, the associations of PLWHA have not only the potential to promote and fight the disease among people in real life but also the capability to construct a virtual community that is part of the real life. The point is, the relationship among people with HIV through PLWHA associations becomes more and more significant. This means the possibility that PLWHA will eventually replace all other forms of associations not composed with people with the virus in the future is evident. This is proven by its new approach which is not only social-oriented but also problem-solving.

The associations of PLWA is formed essentially by poor people has led some to characterize it as a disease of poverty. However, evidence suggests that in some countries the wealthy are also especially susceptible to infection. But in general, it is likely that the poorest sectors of the population are still the most severely affected.

CHAPTER 5 - FINDINGS

This chapter begins with a brief description of the issue of stigma. It gives an overview of HIV/AIDS support groups and how these developed into associations. The comments offered by PLWHA in the support groups and associations are the most important part of this section. The chapter discusses, moreover, questions related to the internal organization of the associations. Also included is a discussion and interpretation of cultural issues obtained from the analysis of People living with this virus. The chapter concludes with a review of the funding in the fight against HIV/AIDS.

Stigma

AIDS-related stigma (or, more simply, *AIDS stigma*) refers to prejudice, discounting, discrediting, and discrimination directed at people perceived to have AIDS or HIV, and the individuals, groups, and communities with which they are associated.

AIDS stigma is expressed around the world in a variety of ways, including:

- ostracism, rejection, and avoidance of people with AIDS (PLWAs)
- discrimination against PLWAs
- compulsory HIV testing without prior consent or protection of confidentiality
- violence against persons who are perceived to have AIDS or to be infected with HIV
- quarantine of persons with HIV.

AIDS stigma is effectively universal, but its form varies from one country to another, and the specific groups targeted for AIDS stigma vary considerably.

Whatever its form, AIDS stigma inflicts suffering on people and interferes with attempts to fight the AIDS epidemic.

Here is a testimony of a man who was diagnosed as HIV positive in Chimoio, 2004:

I never told any body about my situation because I was afraid to be marginalized by them, even my wife I couldn't tell. I only spoke about my condition in the association because I knew that all were suffering from the same problem.

Another testimony quite different from the first one reads as follows:

When the doctor told me that the reason of my long disease was due to AIDS... I informed my husband. Since then, I was no longer at ease at in my house as result my husband decided to take me back to my parents where I am now. My sin was that I revealed the secret...
(Interview with a HIV/AIDS woman in Maputo, 2004).

As one can see, the issue of stigma appears in this second interview. Before, we comment more on the interviews; let us first understand what stigma is all about. Stigma is compounded by fear of an incurable disease, fear of death after long suffering, association of HIV/AIDS with sexuality, and a misunderstanding of its causes. Stigma is indeed deadly because it hinders both prevention of HIV/Aids and provision of quality care. It is also deadly because every human is a social being and when rejected, people become very affected causing death long before the virus could kill. Most of our African countries make the stigma a worse epidemic than AIDS itself (CEA/UEM: 2000).

It is now clear that those who accept their status could live for years, but those who cannot stand the stigma must die earlier than they should. This is very unfortunate because stigma is socially constructed, hence it is curable. An effective way of dealing with stigma is simply assuring people that they are better off knowing their status, that they need not give up if infected, and that there can be quality life after HIV. This is what PLWHA associations are trying to achieve.

These extracts of the interviews demonstrate the level of discriminations related to the HIV positive people, on the one hand, and the importance role played by PLWHA associations where people can talk to one another about their sero status and share experiences.

Origins and motivation for creation of HIV/AIDS groups & associations

The difference between support groups and associations is that the support group is an informal group while the association is a formal group recognized legally by the ministry of justice on one hand, and the existence of structure elected by the assembly on the other. But the objectives, characteristics of the members, the activities are the same.

Some times people of the certain support groups are also members of the associations. It is worth signalling here that most support groups are attached to the hospitals which are their spheres of operation.

The support group origins and function

The establishment of more GATV⁶'s services of HIV-AIDS voluntary counselling and testing help people to check their sero status. These services were created by the CNCS in coordination with the Ministry of Health. The aim of these services to ensure that any one who wants to know about his/her situation does it without any monetary costs. The services are intended to be countrywide provided in order to prevent the spread of HIV through sexual intercourse, maternal-child transmission as well as by blood transfusion. Given this context, the services attempt to reduce the morbidity of HIV- infection through early or prophylactic treatment of HIV infected individual what should include antiretroviral therapy.

According to CNCS, the above services will be provided step by step through the country. They are first guaranteed in the cities where people are the most concentrated. The same source contends that around 2010 these services will cover all health services (CNCS: 2004).

⁶ GATV Is an acronym meaning Gabinete de Aconselhamento e Testagem Voluntaria (Services of Counseling and Voluntary Testing)

Another important aspect related to these services is that wherever they are, they are backed up by **support groups** in order to give an emotional comfort to those people tested positively. As already explained, the integration of people in these support groups is done by GATV services. As soon as people have tested HIV/AIDS positive, they are immediately encouraged to become members of one of these support groups.

There are activists working in these groups whose job is to sensitize people to join the group.

One of the Maputo HIV positive activists went public on her own HIV status and had this to say:

I'm an HIV positive working in this GATV as an activist of this hospital. This job is important because people who receive positive results, if they don't get support of some sort they can even commit suicide. So we stand here as people went through the same experience but alive... and therefore can help others (Interview with an HIV positive activist, Maputo: 2004).

Ivone, coordinator of one of the support group also acknowledges the good results of her work:

I work here as a coordinator of this support group. I used to work for another organization sensitizing people door to door in the community. But when I realised that MSF Luxemburg wants some one for this kind of job, I applied and was accepted. I'm happy doing this because it is a great joy to see that the person who was knocked down by the disease stands up and walks after counselling. It is then that I realised that I am doing a useful job (Ivone, Maputo: 2004).

The drastic growing number of infection in the country and the presence of the support groups can help people to become more and more open and seek for hospitals where they can confirm their status.

It is in this context that Maputo support groups such as Thinhena, Kudunba, Kuyakane and Thinhena youth were found useful to HIV-people. In Manica province there are support groups in Chimoio 'hospital dia', in Manica and Gondola. In Zambezia - Quelimane there is also a support group operating in the 'hospital dia'. Considering the experiences of the already existing associations created from these support groups, it could be assumed that more HIV-associations will emerge in Mozambique. Some of these support groups have contracts with institutions such as Medicos Sem Fronteiras Luxemburg and Switzerland.

One thing that is clear is that none of these messages have led to behavior change. Many of those who were interviewed belong to these support groups and say that they feel secure and happy as members of these groups because they have the opportunity to talk, to share the same situation with others. A woman from Thenema support group confirmed this feeling saying:

When I knew that I'm HIV positive I thought I'm going to die...I really lost the interest in life... but now in this group, I learnt that I'm not alone and I can live longer if I take care of myself (Member of Thinhena, Maputo:2004).

These groups are important because, after a person receives a positive result of HIV feels emotionally down. As a young girl pointed out:

When I knew about my results, I felt abandoned and already dead".
(Member of Kindlimuka, Maputo: 2004).

To elucidate how these support groups operate the author single out *Thinhena*, the group that the author worked intensively with. The author attended many of its meetings and conducted interviews with many of its members. This group was formed in 2000 as a result of the establishment of GATV in health centre of *1 de Maio* in *Polana Canico*. The group is supported by *Medicos Sem Fronteira* Luxemburg.

In *Thinhena* there are more than 90 members that meet regularly weekly following the established calendar:

Monday is the day of general meeting (i.e. for all members of the associations) where they deal with general issues related to their status and the stigmatisation they are victim of in their work places and how to handle that.

Tuesday is the women-meeting day. On this day it is only women of the support group that are allowed to attend this meeting. Ivone Joaquim coordinator of this group says that she understood that women in the general meetings didn't speak comfortably about their problems. This attitude is caused by gender- power relationships already emphasised on. Women are afraid to expose their ideas and tell their experiences because they can suffer some reprisal from their husband at home.

Wednesday is the day of youth meetings. These meeting involve both boys and girls. Specific problems related to their age are discussed. The major concern of this group is to create awareness of how they have to deal with their future despite their status. Issues around marriage and education are also discussed.

On Friday pregnant women attend the (PTV⁷) *Programa de Transmissao Vertical* 'Vertical Transmission Program'. This program of prevent mother-to-child transmission of HIV is supported by USAID in conjunction with the Ministry of Health and others partners. This started in 2002 most in urban areas making a volunteer counselling and testing available for pregnant women as part of antenatal care including greater use of safe delivery services, family planning to reduce mother-to-child transmission, and anti retroviral therapy (Nevirapine) for these positive pregnant women (USAID country profile: HIV/AIDS). Beside all these aspects is also including counselling on appropriate infant feeding.

As women are taught not to breastfeed their little ones and knowing that the level of income for most families in Mozambique is a problem, it was found that such meetings

⁷ An acronym in Portuguese meaning Programa de transmissao vertical what means in English program of vertical transmission. This program is about pregnant women attending the treatment as a way to avoid the transmission of the HIV to the baby.

be done in conjunction with some NGOs such as Santo Egidio and World Food Program in Maputo and Quelimane that supply milk to these babies till six-eighteen months though these programs do not still solve this problem given the fact that babies need milk up to two years. The question is often what will come after six months?

Vigorous controversy exist about whether HIV infected women in developing countries should choose the formula of breastfeeding their infants or not. Breast milk, as we all know, especially in the first months, are vital for the survival of the child because it contains nutrients and antibodies which are needed for the development of the immune system of the baby but have inherent risk of transmitting HIV to the baby. Not breastfeeding babies eliminates HIV transmission but incurs risk of increased mortality whereas breastfeeding has multiple benefits but entails risk of HIV transmission it is estimated by UNICEF that million non –HIV related death per year can be prevented globally through breastfeeding (Coutsoudis, 2002:15).

The other problem is that when infected women are asked why they don't breast feed their babies they have difficulty to explain the reason. Confidentiality is also at risk. Pressure from family especially mothers - in -law force young women to breastfeed thus, increasing the risk to their children to be infected.

From the support groups to the associations

According to the interviews support groups decided to become associations because they felt the necessity to act outside of the hospital and be recognized as groups which have the capacity to talk about situations on behalf of people living with HIV. They started to be organized in way to act outside the hospital, integrating both infected and affected people suffering from the same problem. They were encouraged to establish their own associations.

Then some members start to follow the necessary path to create a formal group with their own vision and specifics aims. Are examples Thinhena and Kubumba in Maputo.

«..we thought to create our own association to explain our situation to whom it concern...and we wanted to be recognized as a organized group

of one's own free will to fight against HIV/AIDS breaking the silence(...) another problem is that the donor institutions only give support to organized groups and recognized by the government...». (Elias president of Thinena , Maputo:2004).

This is confirmed by Elias in Thinena association who says:

We thought to create our own association to explain our situation to whom it concern...and we wanted to be recognized as a organized group with our own free will to fight against HIV/AIDS, breaking the silence(...) Another problem is that the donors (institutions) supported only formal organized groups recognized by the government. (Late Elias president of Thinena association, Maputo: 2004).

Rensida, a national network of PLWHA has been useful by supporting some groups preparing their documentation to become associations. This national network has been supporting also in writing projects and finding donors to support these associations. The most important role of this national network is to co-ordinate the activities of its members, on one hand, and to represent interests of its members in the government and others institutions. It is in this spirit that associations such as Thinena and Kubumba in Maputo were formed.

Overview on the associations

In Mozambique two phases can be distinguished in the creation of HIV associations. However, our purpose is to highlight them and the different metamorphosis they took overtime. The first category could be sent back to 1997-9 when timidly people of HIV/AIDS formed the first associations. In this time these associations were hidden and only people directly related to them knew about their existence. Some NGOs and others institutions were behind the creation of them stimulating PLWHA associations to work with. Later on, these people decided to organize themselves into their own associations. Examples can be given of *Kindlimuka* in Maputo in 1996 and Kubatana in Chimoio in 1998. This word '*Kindlimuka*' means in Tsonga 'wake up'. In other words, it is an invitation to take action as time has gone.

This command fits very well in the context of HIV/AIDS matters where people need to wake up and fight against HIV. Kindlimuka, the first group of its kind in the country, was founded in 1996 and officially recognized in 1998. Today it has more than 330 members, of whom the great majority is HIV-positive. The association strives to reduce the stigmatization of people living with HIV/AIDS by breaking the silence and speaking openly of the illness. It encourages other groups of PLHWAs to seek official status for their associations with the aim of establishing at least one association for each province in the country.

Rudo Kubatana in Manica province is the other association belonging to this phase *Rudo Kubatana* in *Shona* language these words are expressed to encourage HIV positive people to stay together in love ‘people has to be together and in love with each other’⁸.

Associacao Esperanca in Quelimane-Zambezia also means in Portuguese language ‘Hope Association’. This is a challenge to HIV- positive people to think positively and be full of hope for future despite their condition.

The objective of these associations was to give the membership courage and hope. The native names given to theses associations attract local people who deeply understand the meaning behind these names. However, the idea that PLWHA associations can help HIV-positive people is not new, nor is it exclusively African. It does exist in other places as well but seems to be a successful approach in the Mozambican context. The success rests on the fact that most HIV-people feel free to share their burden with their peers who suffer from the same disease.

The second generation of associations of PLWA can be considerate since 2000 until nowadays, in this period observed a “boom” of these associations, the reasons behind this increasing of associations could be associated to the awareness of the government with

⁸ This explanation was given by the president of Kubatana association in Chimoio during the interview in 2004

this pandemic that culminated with the creation of the CNCS⁹ in 2000 a governmental institution with the task to coordinate all actions related to HIV/AIDS countrywide. This measurement shows that the government was committed now more seriously. The HIV/AIDS was assumed as an emergence national matter so including in the priorities of its agenda. (Plano Estrategico Nacional: 2004)

PLWHA as a tool to Breaking the Silence on HIV/AIDS Epidemic in Mozambique

As the fight against HIV/AIDS intensifies in Mozambique, more and more people living with the virus are volunteering to share experiences but we should admit that this is still happening in the confines of these associations or support groups mentioned above.

Janzen in the quest for therapy in lower Zaire found that the people with the same problems, are more confident and the communication becomes more simply when they share the same culture .(Janzen: 1978).

As long as people are ready to talk about it, HIV/AIDS has spread at a fast rate in this country. People living with HIV/AIDS in the associations share their experiences with one another. This indicates that people start now to accept the reality of HIV/AIDS and respond with full understanding of the complexity of the epidemic and the socio-economic challenges it is posing to the nation.

These associations are the best way to deal with HIV as many people make their HIV status known there. The associations also present talks to various groups, help organize HIV/AIDS awareness and education campaigns, and provide HIV/AIDS pre-test and post-test counseling and psychological support to those infected and affected. It is believed by many that people living with HIV/AIDS are potentially the most effective educators, counselors, campaigners and care givers given opportunity and support.

⁹ CNCS Conselho Nacional de Combate ao Sida is an acronym in Portuguese meaning: National Council of Fighting AIDS.

People living the virus are starting now to make HIV/AIDS visible through personal testimony, using sensitive training, prevention campaigns and workplace counseling to bring AIDS into the open and encourage an effective and humane response by governments and civil society.

But their meetings remain the first place where the silence is broken because they are open in speaking about their problems. Those who have lived with disease long enough share their experiences with the new members to encourage them. A senior woman of Thinhena support group declares this, for example:

Times ago people in my district used to point fingers to me saying that she has AIDS. I was ashamed about, but now when I hear some one point to me in that way I confirm my status and I advice him/her to go testing because he can be also in the same situation like me....(Amelia, Maputo:2004).

The whole idea is to give a human face and voice to the epidemic in the minds of people not directly touched by it, "We want to facilitate the acceptance of the presence of HIV/AIDS in the community" (Onen, 1999:2). The more we start talking about the epidemic, the more people will accept it as a reality and refrain from behavior that would put them at risk.

Those in positions of power should strengthen the capacity of communities to discuss the epidemic and the changes they must introduce to survive, and increase effectiveness of national HIV/AIDS policy development programs as the community-based organizations (PLWHA) have started to show the example with its counseling and care activities programs.

Intellectuals should also contribute their knowledge and experience to decision making processes to ensure effective national response to the epidemic. We need to know that we are all at equal risk contracting the virus. Above all the government must make information and tools for prevention and support available to all citizens, increase investment in programs for young people, promote the development and implementation

of policies and legislation that will ensure the epidemic attains priority in the government's budget.

Characteristics of the members the Association

I attempted to gather full data on the characteristics of these members including sex, age, level of education and employment. However, because of different reasons such as the lack of update data base of associations, it was not possible to find these aspects in all associations. Except in two associations *Kindlimuka* and *Associacao Esperanca*, it was possible. The presentation of this data is an attempt to give a picture of what these associations are like. This data is reliable because it is full of inconsistencies.

Characteristics of the associations

Organizations.	Location	T. number	male	female	employment	education
Kindlimuka	Maputo	330	124	206	85 ¹⁰	¹¹
Kubatana	Manica	138	66	72	65 ¹²	
Shinguirirai	Manica	100	40	60	25 ¹³	
Associacao E	Zambezia	350	150	200	22 ¹⁴	50% ¹⁵
S g. kudumba	Maputo	About 50 ¹⁶	32	18		
Thinhenha	Maputo	80	30	50	80% - 15% ¹⁷	

Table 2 characteristics of members of the associations

¹⁰ This number of people employed in this association seems to be high because it includes activists

¹¹ Information about education is not possible to be presented in the table because the data are estimated. For example, the number related to high education is referring to honorary members, while, 35% of the members in these associations never been in the school

¹² Most of them as activist employed through the association

¹³ All employed as activists

¹⁴ 17 of this number are working as activists 8 outside of the associations

¹⁵ 50% are illiterate while the other 50% attended primary school and a few % secondary school

¹⁶ Means that was not possible to get the precise information due to the fact that some member no more attend the meetings of the group

¹⁷ This association estimated the data in % where 80% are unemployed and only 15% employed

Associations must be managed and run primarily by People Living with HIV/AIDS, both affected and infected but mostly the infected ones. They must have or establish a board and officers, as well as an elected finance sub-committee, and a medical advisory team. They must also keep minutes of board meetings and up to date financial records. Associations must demonstrate that they do not discriminate on the basis of gender, religion, ethnicity, sexual preference, and social class; or against sex workers and drug users. The selected members should have demonstrated commitment to their own health by their past and present behavior, such as participation in the association's Positive Living programs.

In short these groups can be represented as this:

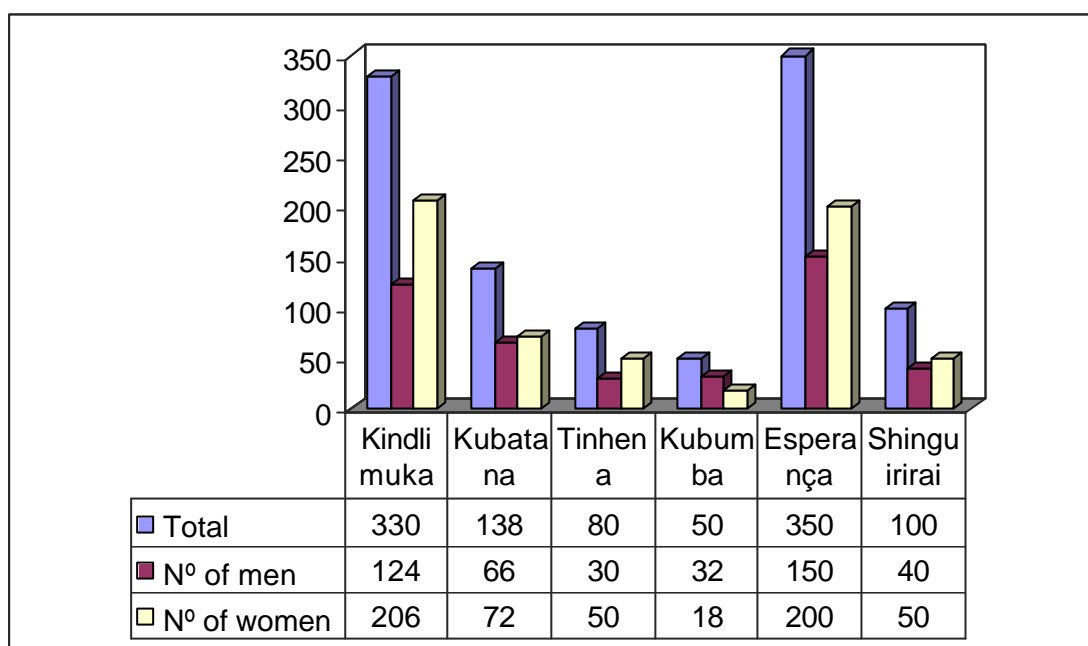


Figure 5. Distribution of Males and Females in the Associations

Gender Issues in the associations

Following the above tables, it is clear that the number of women in all associations is higher than that of men. This is because women find themselves in situations where they need to be tested than men do. They get tested when they are pregnant, they are advised to have an HIV-test and if they are found positive, they are integrated in the associations. Patton confirms this when she says that “many times these women are surprised confront with this situation in conjunction with undergoing some other forms of health care mostly related to their reproductive health” (Patton, 1994:128).

But beside these reasons the number of women increases in the associations because some of them are taken by their sero positive husband advised in the hospital to check their wives' status. By contrast, women do not have enough power to bring their husbands to the associations. An HIV-positive woman confirmed that when she knew about her situation, the hospital advised her to take her husband for testing. The husband in return responded angrily saying:

get out from my home, I don't want to hear this in my place if you have got AIDS it is your problem don't include me in your affair

As already emphasised in chapter 2, the relationship between women and men in Africa are characterised by asymmetrical power relations, which constitute real barriers to women's social development. Women are always silenced by men in many aspects, especially when it comes to sexual matters.

In fact, if we accept that the most important means to transmit HIV/AIDS is by heterosexual where both men and women can be affected the gender relations are indispensable to be considered. In African society the "women often have too little power within their relationships to insist on condom use, and they have too little power outside of these relationships to abandon partnerships that put them at risk" (Baylies, 2000:6).

Even as Baylie and Bujra think that the best thing to do would be for women to challenge men's power and negotiate for safe sex (Baylies&Bujra, Xii: 2000). But this challenge is not an easy task considering the process of socialization in Africa including cultural practices such as polygamy and rites of passage (initiation rites) that put women more and more in subordination conditions. In these practices women are taught to surrender before the male power if they have to be good house wives.

In almost all African cultures, "women's worth is equated with their child bearing and proofs the men's masculinity (Patton, 1994:140).

To confirm and reinforce this argument it could be important to state the following quote from one of my interviewees:

I'm 29 old and have got three children. The oldest is of my first marriage. He is 14 and another is 9 and the last is this baby here. These two last are of my second marriage. My husband died five years ago. I was always sick and had a skin disease (herpes) and TB as was diagnosed at hospital. I was convinced that I will soon die because I had the same symptoms which my husband had.

Given the persistent of my illness I had to consult the doctor and he advised me to take a HIV test. I did and the results were positive. Finally I was told that I'm HIV positive. At the hospital I was advised by an activist of Kubatana to join his association. So, after the first visit, I decided to be a member of this association. The first day when I get there I recognized many people there because some of them used to come at my home with my late husband as his colleagues. So I realised that every day when he said that he is going to work, he was actually coming to the association. I remember that he never told me where he was working and what kind of job he was doing. My husband was HIV/AIDS positive and he knew it, but never told me about his status. The life at home was natural until he died. Now I have another partner and I got this baby but last year my baby died. We are together in this association....

When asked if she knows that it is not good to have babies because they can die as result of this sickness, she replied:

I know, at hospital they teach us about these things. They say that it is not good for an HIV positive to be pregnant because the body will get weaker and weaker and eventually die. But what will I do? I'm still young and my husband says that he can only pay lobola (bride price) at least if I have a child with him.

In my family no one knows about my situation. It is not easy to tell people about this disease here in Chimoio because you can be discriminated by all people including the family members. Now I'm working here at the association as a cleaner as a way to have some money to support my children.

We speak of African women as being sexually subordinated by men. That topic is also debatable because on the biological point of view, women still have an important role in African society. A proverb from Ghana declares that: A woman is a flower in a

garden; her husband is the fence around it'." (1). That is a beautiful picture of women in African society. The main idea here is to link human life directly with God through the woman. She is created by God, and in turn becomes the instrument of human life. She rightly becomes the one who passes on life. With such a belief, African people both men and women see the bearing of a child is very important than the fear of having one's child infected by HIV/AIDS.

Level of education

The second aspect that comes out from these associations is the level of illiteracy. A country in which 70% of the population resides in poverty and illiteracy the disease (HIV/AIDS) can only be expected to be rampant. This is so because the community has no exposure to programs that can help them and inform them to fight this pandemic and therefore the risk of vulnerability of infection will continue unless alternative measures such as the ones by PLWHA are effectively adopted in the entire country.

There are many reasons for AIDS education. The first of which is to prevent new infections from taking place. People should be given information about HIV, how it can be transmitted, and how people to protect themselves from infection. A second reason that AIDS education is needed is to improve quality of life for HIV positive people HIV+ people should be taught about the importance of not passing on the virus. The third reason people need AIDS education is to reduce stigma and discrimination. In many countries there is a great deal of fear and stigmatization of people who are HIV positive.

This fear is too often accompanied by ignorance, resentment and ultimately, anger. Sometimes the results of prejudice and fear can be extreme, with HIV positive people being burned to death in India. Discrimination against positive people can help the AIDS epidemic to spread - if people are fearful of being tested for HIV, and then they are more likely to pass the infection to someone else without knowing (HIV&AIDS Education, 2005)

It is a fact that the people who are most urgently in need of HIV education and in these associations are poor or ordinary people. Those educated people who hold high positions in the government or local authorities though HIV+ are completely absent in these

associations. They get their assistance or treatment from private clinics or outside the country. This is so because of the fear of discrimination in Mozambique.

Unlike these educated people, the uneducated ones feel free to talk about their sero-status. They appear on TV programs confessing publicly being their sero status. TVM program “Vidas positivas” makes efforts to bring middle class people to do the same but they timidly respond to this program’s invitation. Maybe the reason why the poor people easily break the silence is because they have not much to lose and in so doing they know they will maybe get some money or others forms of compensation to face the starvation problem.

This was confirmed by two young boys in Chimoio who told that when they broke the silence by declaring their HIV status they used to receive some incentives.

“... when we gave this kind of information about our HIV status we used to ask for some incentive... and coming out in the open is not easy... many organizations used to give us some money...” young boy from Guinguirirai Association, Chimoio: 20004).

From a handful of courageous individuals who went public about their HIV status in 1999 in the capital, Maputo, there is now a nationwide network of 28 associations of people living with HIV and AIDS (PLWAs) (Rensida: 2004). Yet stigma and discrimination persist.

Considering the level of education and employment, one can conclude that these associations are weak. On one hand, it is not easy to do voluntary work and the same time try to feed the family since the majority are unemployed and on the other hand, because the members are illiterate, they can not make well-informed decisions in the running of the associations.

The general picture of Mozambique is that is a poor country ravaged by AIDS with a high employment and low education level. Despite this picture, there are some rich people in good positions in the government and civil society. Although these may suffer from AIDS, usually they do not belong any of these associations.

This kind of attitude is not good when you want to break the silence. Mozambique is still not doing well in breaking down the culture of silence among influential people. The experience of Uganda shows that when influential people come out in the open and announced their HIV/AIDS status, more people were influenced to do the same. It also led to an increase in sensitization of the general public on issues that relate to HIV/AIDS.

Organizations like TASO and individuals like Pilly Lutaya in Uganda “ put a human face to HIV/AIDS” . Ordinary people were able to associate AIDS with rich people, and joined hands together in fight against HIV/AIDS. (<http://www.aidsuganda.org/pdf/role-ofvct.pdf>).

Unlike Mozambique in many countries such as South Africa we hear stories from people who live or have in some way been affected by HIV/AIDS. They reveal their status honorably. However, for the vast majority of people living in these counties, human rights are respected and people have learned to live with HIV+ people with dignity. This is a good example to follow for Mozambique where everyone needs to learn how and why not to discriminate against positive people.

Altman comparison of HIV organizations in Africa with those in USA found that in the USA these organizations are far stronger and organized in terms of political representation and advocacy than they are in Africa or other developing countries (Altman: 1994: 58-59). In our understanding what makes them this way can be attributed to wealth, fight against discrimination and high level of education of those working in these organizations.

Employment and HIV care

HIV-People in Mozambique, estimated at 13% of the total population within a country continue to face difficult lives without access to any basic services.

Education, Transport, Health and Employment services do not exist or are very scarce and do not satisfy the needs of this social group. The mass media do not give attention to the specific needs of people.

Mozambican society in general, continues to look at people with disability including HIV- people as useless and incapable; subjects them to constant marginalization and discrimination; and gives them no space to participate in the massive effort of recovery and development of the country.

It is important to observe (see tables 1-7) that most members of the associations are unemployed. In this item we used two categories of employed people: one referring the people employed outside the association in public, private or informal sector, and the other referring to people considered employed by the associations working as activists in the GATVs or hospitals. Since they receive their minimal incentive, they consider themselves as employed people.

This incentive correspond about 500000\$00mts equivalents about R 150\$00 per month. This amount is insignificant if it has to cover the needs of a household with at least 5 to 6 people. In INE and PNUD report, Mozambique is considered as one of the poorest countries in the world where people are living with less than one UDS dollar per day. The actual minimum salary in Mozambique is 1.200.000mts meanwhile the basic needed for a household of 5 people are calculated in double of minimum salary in 3.300.000mts (OTM Cental Sindicato: 2003)

Given the low possibilities of employment most people in these associations are concerned in having this kind of job as an activist and they consider themselves as employed despite this low income.

For example in Maputo the coordinator of the Kudumba support group, said that when the association was formed most of members got employed as cleaners or gardeners at the hospital where the association is based. That attracted other people to join the group so that they could benefit from the incentives. It, was not possible to employ all or the people because the jobs were limited (coordinator of Kudumba, Maputo: 2004).

It is in this regard that the board of the association came to the understanding of the fact that people working in the association with children to look after qualify (should obtain)

for such support grant for survival. The president of association Kewa in Quelimane argues:

One of the most important objective of the association is to ensure that the members have the minimal for survive... many of us are not working because we lost the job due to the illness... so we have to do something for them in that way (Ana of kewa association, Quelimane:2004).

In this way, we see the PLWHA as having gone one step further from their emphasis on HIV/AIDS education to care. Education was (is) important, but now that the pandemic is full-blown, the need for care had become more urgent.

In South Africa a disability grant of R740 per month (US \$108) is available to people with CD4 cell counts below 200. It is believed that HIV-people who cannot work find themselves in the category of those with disability and are eligible to such grant.

Unfortunately, there are some misconceptions among the young girls who sleep around with men without condom. They do not mind contracting HIV so that she could access the disability grant. Here also the South African government (the department of social development) has the duty determine how to improve the grant system and prevent such perverse incentives.

Caregivers need to receive a salary, which can help them and their families to survive. We do, however, agree with the fact these people have been trained in basic nursing skills, but are not health educators or full nurses as such. But it is also true that they cannot work for nothing.

In short, a number of issues impinge on the PLWHA's contribution to HIV/AIDS. High illiteracy rates, unemployment, underemployment, lack of scientific awareness of HIV/AIDS epidemic, a high population growth rate and cultural misconceptions, are some of such issues affecting the policy that PLWHA proposes to address.

Description of the association's offices

This section describes PLWHA addressing HIV/AIDS in Mozambique that were visited during my research in Maputo and other provinces. The offices outlook, the associations' functions and chart will be presented as well.

To start with, most of the offices of the associations are small houses in annex of the main house (dependencia) and in degradation situation (i.e. without renewal painting, electricity and water) with the exception of kindlimuka in Maputo and kubatana in Chimoio whose offices are independent properties.



Figure 6 This is the office of *Kindlimuka* association with the logotype in the main entrance

But both of them faced some problems related to the payment of the rents. Kindlimuka , for example, moved twice from one office to another in 2004. Kubatana was in search of a less expensive and affordable office as their donor notified them that he will stop paying the rent simply because the association mission in the province was nearly to finish

Others associations work together with NGOs or other institutions as they are unable to afford the rent. This is the case of Guinguirirai in Chimoio working at Kubatsirane office. Kuyakana in Maputo is also working in the premises of the Rensida office while

Associacao Esperanca is with MONASO in Quelimane. And finally Kewa in Quelimane is given a small room in the provincial hospital.

It is also important to emphasise on the fact that these offices are located in hidden places. Is not easy to find them unless one is taken by hand to these places as they do not even have the advertise signals pointing to where they are located.



Figure 7 the road to get the *Thinhena* association some where in the district of Laulane close to Maputo city



Figure 8 The *Thinhena*'s office association

Mozambique faces many challenges. Even though PLWHA continues to play a paramount role in educating people about HIV/AIDS and sharing of experiences with the government, the political parties about this pandemic.

Structure and function of these associations

The way in which HIV people associations are structured is based on the one adopted by the most of NGOs in Mozambique. To be legally recognized an association in Mozambique an organization has to be recognized by the ministry of justice. Ten members at least have to sign the status in representation of the others members. Others requirements are: the *estatutos*, describing the aims of the associations, general presentation about the members, the structure of function of the different organs.

The basic organization chart looks like this:

The structure of the organisation: Principal organs and the function

Organization Chart

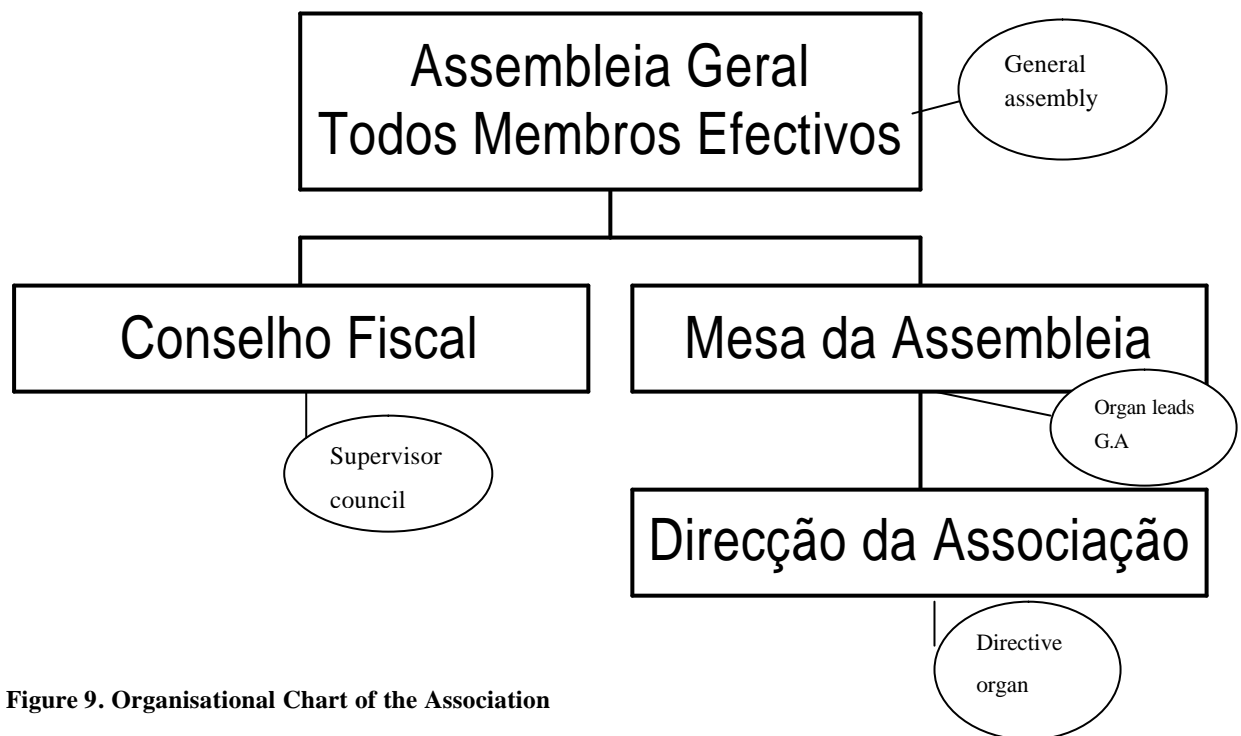


Figure 9. Organisational Chart of the Association

Sources: This organization chat was based on different status of the association (Thinhená, kindlimuka, Muleide, AMMe, kubatana).

Function of the associations

According to this chart the principal organ is the **General Assembly**, a president supported by one vice president and one secretary composes the presidium of this assembly. This is the main organ because it is where all aspects regarding the life of the association are being discussed. The alterations of the status, admission of new members, examination and approval of annual activities reports as well as financial reports are also part of this organ's agenda. The ordinary meetings occur once a year while the extraordinary can occur anytime when required by the direction or by 1/3 of its members.

Below the general assembly comes a **Directive Organ**. This one is composed by a president, one or two vice presidents and the executive secretary. This organ is the executive structure that deals with the daily activities of the association. The directive organ represents also the interests of the members. It is, in addition, responsible of the mission and vision of the association in the country and outside.

The **Executive Secretary** is not elected in the general assembly; he/she has to apply for this position according to the requirements set up by the association. The secretary spends her/his days coordinating meetings, making travel arrangements, and managing schedules. In between, she answers telephones, emails, and faxes. His/her major function of the Executive Secretary is the coordination of activities from the association's members, donors, and the international organizations.

The other important organ is the **Supervisor Council**. It is also composed by three members who are: the president of the council and two vocals members. This is also an important organ because it supervises all the activities of the association.

Normally these organs have the duration of three/ four years. Candidates of different organs have to observe three conditions: (a) to be effective members, (b) to be a HIV+ and (c) have leadership qualities.

As far as the schedule of other organs is concerned, their members have specific meetings weekly. They also have sometimes meetings with the directive members to analyse different activities.

As regards **the membership** of the association, we distinguish three general types, which are:

- The effective members,
- The honorable members and
- Sympathetic members.

The effective members are all HIV+ people who identify agree with the aims and objectives of the association. They are the key members not only in terms of numbers but mostly because they are the real cause of the existence of the association. Most of them are recruited through the activists working at the GATVs services. These activists start by presenting their associations and explaining the advantages of being member based on their own experience. It is in this way that they have been able to convince and attract as many people as possible. The process of becoming a member usually follows the same pattern. One member explains this process as follows:

[...] In 1999 continuously suffered from malaria and headache. I was also losing weight considerably. The medicine I was taking didn't solve the problem, so the doctor advised me to take a HIV test... the result was positive. Before the test I was asked by an activist of Kindlimuka to be a member of this association, and I joined.

Another member in Manica explained how he became a member of Guiguirirai in this way:

I took an HIV/AIDS test because I was always sick. I was told by some activist of this association about the advantages of being in this association. So I decided to visit the association and later I became a member...

Most people become members of the association after being referred to them by activists in the hospitals and GATVs. Stories such as these are numerous. Two aspects came out: the first one is that people normally go for a HIV/AIDS test when they got a persistent disease. The other aspect is that people become members of the associations because of the job of the activists at the hospitals inviting HIV positive people to join these associations.



Figure 10. Members of Kindlimuka association in the office.

Honorable members are people with influential positions in the society. These are, for instance, the members of the government or the civil society. In the Kindlimuka association we have members such as the prime minister, the minister of health of Mozambique, and the national head of HIV programs in the health ministry. There are also members of international agencies who contribute financially for the advancement of the association.

We have finally the **sympathetic members**. This category includes people working in the field of HIV from different sectors of the society as well as people working in the health services. It also includes anyone interested in HIV matters.

Rights and obligations of members

To be involved in the activities of the association gives one the freedom of speech in issues related to the association. Any member is in the obligation of paying a symbolic amount of 1000.00mts (i.e. some cents if converted in South African rands) as a symbolic contribution to the association.

Being a member of an association is very beneficial. One of most important benefits could be to access automatically the ARV treatment but is not what is happening. The government has a policy on the provision of antiretroviral treatment (TARV) that

involves these associations. The section of the Anti-Retroviral Treatment in Mozambique (Section 4.4.3.1) below expands more on the benefits of being member of the association and the role of this treatment.

The association and the Anti-Retroviral Treatment

As part of their rights members of these associations stand the chance of benefiting an efficient HIV treatment.

In theory, there are 3 strategies to contain the HIV/AIDS epidemic:

- To vaccinate everyone against HIV;
- To change sexual behavior;
- To provide anti-retroviral therapy (Gorik Ooms, 2004).

Of these three, the two first will take time before the change occurs. The countries, who favored the prevention via change of sexual behavior such as Uganda, now start to upscale anti-retroviral treatment. Effective anti-retroviral treatment seems to be the best option today but it requires patients to know their HIV positive status in an early stage of the syndrome.

Kindlimuka and GASD were among those associations that tried to address this issue of anti retroviral treatment in their programs. But according to the rules of the country the anti retroviral treatment (TARV¹⁸) is administered following the principles below:

To be eligible for this treatment one must fulfil the following:

- The confirmation of HIV/AIDS positive test by any national service of health.
- The level of CD4¹⁹ cells must be tested below 200 (point which indicates AIDS).

¹⁸ TARV is an acronym in Portuguese meaning Tratamento Ante Retroviral translated to English could be Anti Retroviral Treatment .

- Have at least one individual around who can assist in administering this treatment.

It should be noted, however, that this treatment is provided to all those who are infected by HIV independently if is or not a member of any association. This program is in the responsibility of the Ministry of Health. The ministry has a national program for this kind of treatment. There exists a specific program that is at the disposal of the members of HIV /AIDS people that belong to the associations. In other words, this treatment does not privilege any one but every body has right to it.

According to this ministry the TARV already started in Mozambique in 2000. Each hospital receives for the TARV program at least 75 new cases per month. In all provinces the workers of this program confirmed that people are really adhering. In Chimoio, for instance, the Dia hospital receives more than 75 new cases per month because this Hospital has been receiving also patients from different districts of this province. (Interview with the director of health, Chimoio: 2004).

According to some patients the effects of this treatment are visible and the treatment is therefore seen as effective. One of the patients at Maio Hospital acknowledges:

[...] when I started this treatment, I was too slim I couldn't even work, my mum had to carry me like a baby...but now, as you can see, I'm now putting on some weights ... people don't believe that I am sick (A patient of I de Maio hospital and member of support group, Maputo:2004).

However, to be administrated such a treatment, it is important to be aware of its side effects. Therefore one needs to feed on a solid and nutritious diet. But as many people live under poverty in this country, we believe that starvation could be also the major reason for deaths. On the other hand, interrupting such a treatment does not help the patient at all, it does, instead, create the virus' resistance to the medication.

¹⁹ CD4 or (t cell) lymphocytes are a group of white blood cell that normally help guard the body against attacks by bacteria, virus and other germs. When CD4 has decrease progressively to 200 cells or below the person has developed AIDS (<http://www.intelihealth.com/IH/ihlih/ws/h www/>)

Anyway, Muleide, an activist working in some suburban area in Maputo one said that people in general are reacting well to the TARV programs. Another aspect to it is that, the experience of care home-based care services are applied in so many developing countries because the health services cannot afford to deliver their services to a huge number of infected people. As a new experience there are some difficulties in dealing with them. That is why it is accepted that HIV associations deal also with such cases though requiring a little bit of expertise that most activists do not have.

The important is that the ART is shown efficient to minimize the AIDS. People who already started this treatment have given good reports. The Mozambican government is lobbies also to have more money in order to subsidize these drugs for more HIV positive people. The actual cost of ART treatment in Mozambique is about \$ USD 250 year per person. Is too expensive for a poor country like Mozambique, that's why the CNCS National council of fighting HIV/AIDS assumes that the first strategy should be the prevention. (Plano Estrategico Nacional: 2004).

Activities & responses of members belonging to the associations

Much of the counseling, education and peer education work which is carried out with HIV positive people is conducted by HIV positive people. Many projects are shaped by HIV positive people themselves, given the insight they have into what it is like to live with HIV / AIDS. A good example of such a service - run by HIV positive people for HIV positive people - is *Kewa Association* in *Quelimane* where one of the members stresses the unity among members in the following terms:

*Here we are like brothers and sisters. We use to come here to talk each other because at home we don't have the same comfort we have here
(Member of Kewa association, Quelimane: 2004).*

The other membership expressed also his feeling in these terms:

I can't lie to you. I'm feeling much better here than at my own home. Here I got friends with whom I can joke and talk bout any thing... So, I come

every day here and spend my day joyfully (Kewa association, Quelimane: 2004).

In short, these associations in all the three provinces are developing the same activities:

- Mutual support in the association through home visits.
- Educating people at the market places, in schools, workplace by making use of themselves as examples of HIV positive people.
- Giving counselling at the services such as GATV and hospitals.

The activists of these associations receive themselves a special training from national organizations such as AMODEFA and MONASO working in conjunction with the ministry of health. The activist's visits not only are important for the patients suffering with AIDS but also by enriching contact with the family members and advice about the illness. In so doing they help those who are not sick to know how to support the family members who are infected by AIDS. They become aware of how the disease is being transmitted and reduce the fear they might have by increase their compassion and cooperation for the patients.

It is worth repeating that civic education plays an important role in sensitising people about HIV/AIDS, especially when it's being conducted by an HIV/AIDS infected person. The message has greater impact on the audience because the messengers talk about their own experiences as people who live with the disease.

The home-based care and treatment is very important in many respects. Firstly, it enlightens the family members who are ignorant about how HIV transmitted. Secondly it helps in teaching family members to be compassion to HIV/AIDS patient because the activities are compassionate. It can be agued that the home based care treatment in Mozambique is supplemented by grassroots organizations. So, it is believed that this treatment can become more and more effective and sustainable if grassroots organizations are linked to existing public health services. However, this linkage is not effective because the public health care services are inadequate and insufficient.

The other activity undertaken by these associations in order to sustain them is income generating activities. These include the following:

- Embroidering and weaving different materials for sale
- Selling traditional medicine which is extracted from African potato
- Subsistence agricultural activities

In brief, this grassroots' action and other activities have an impact on PLWHAs by providing secondary income to sustain them.



Figure 11. These members of Kindlimuka Associations sewing staff of selling



Figure 12. *Some member of Thinhena association making vases for selling also*



Figure 13. This picture also is showing a group of women swing

Family: An important source of support for HIV-positive People

People diagnosed with HIV often turn to friends for support, and that's encouraged by doctors and therapists. But Ohio State University research suggests this advice may not go far enough. In Serovich's most recent study, published in the journal *AIDS CARE*, she found that the 134 HIV-positive men were less likely to be depressed if they received support from their families. In another study of 142 HIV-positive men, published in *AIDS Education and Prevention*, she found that subjects who received social support from their families were less likely to engage in risky sexual behaviors than were men who did not get social support from their families.

Serovich does not say that all HIV-positive people should tell family members, nor does she believe all family will be supportive. Some may, in fact, be hateful. So, HIV-positive men should consider seeking guidance from therapists or other helping professionals in making decisions about disclosure to family. And therapists need to encourage exploring those options.

People often need help in figuring out how to disclose their HIV-positive status to anyone, and it's important that they do so. It has been observed that people who disclose their status are more likely to get necessary medical help and find out about clinical trials, new therapies, family support or other options available to them than those who do not disclose their status.

In most cases HIV family members in Mozambique have problems supporting their family members who are sick. This is partly due to lack of knowledge of how to deal with the sick, on the one hand, and to lack of disclosure of those who are sick to their family members, on the other. In fact, many of these HIV positive people argue that it is difficult to inform the family members about their status as well as involving them in the association except in cases where the husband was tested positively and the GATV advises him to bring the partner and this one is also tested positive. But generally speaking families are not involved as pointed out by a member of Esperanca association who once said that

My family doesn't know that I belong to this association. In fact, I never told them ...not even my wife. Because I don't know how they will react (A member of Esperanca association in Quelimane: 2004).

In Chimoio a member corroborates this idea when she says that

I didn't know anything about this disease until my husband who was always sick and had skin problems for years asked me to go with him to the hospital one day. There I was tested HIV positive. He finally revealed to me that he was he also HIV+. This is how we are together in this association (An HIV positive woman in Chimoio: 2004).

This shows how women rarely learn about their husbands' status.

In cases where the woman goes first to the hospital and asks her husband to attend the consultation at hospital this one often responds in these words

You, go if you think you are sick, I'm fine (A member of Thinena support group, Maputo: 2004)

It is clear that the power of the man surpasses that of the woman in Mozambican patriarchal society as such man has a power to influence his wife to go to the hospital and not vice versa.

The anti-retroviral treatment referred to in section (4.4.3.1) requires that family gives support to HIV patients. In fact, when people start the TARV treatment the health service worker obliged them to tell members of their families because of this treatment once started it cannot be interrupted, and these drugs can bring out collaterals symptoms that it becomes therefore important that the family member encourages the patient to go further with it. The counsellors in Maputo association are aware of that as one of them remarks

When people have to start the TARV treatment we require that they come with at least one family member to will be looking after the patient at home. This person needs to be informed about the TARV treatment and its

effects in order to assist the patient whenever he needs help (Officer of MSF, Maputo: 2004).

It is wrong to assume that family support is mostly needed when the patient goes through the anti-retroviral treatment. This support is needed even for orphans (victims left behind by HIV/AIDS deceased parents).

Support for orphans by family network

While we praise Mozambique for its initiative to create its first hospital for HIV-positive children officially opened in Maputo on 24 May 2004 as the country was struggling to cope with more than 30,000 children born each year with the virus that leads to AIDS, we encourage the country to make however a further step. In fact, one of the most devastating aspects of the HIV/AIDS epidemic today is also the growing proportion of children the disease has orphaned. Unlike most diseases, HIV/AIDS generally kills not just one, but both parents. What is more, the stigmatisation and discrimination that people affected with HIV often live with is passed onto their children, making their fight for survival much more precarious.

When parents or caregivers fall sick and die, a child's life often falls apart. With HIV and AIDS, the hardship hits well before children are orphaned. First a parent or caregiver becomes ill with HIV or AIDS, and is unable to work. The entire family feels the economic impact – children, especially girls, must often drop out of school to go to work, care for their parents, look after their siblings and put food on the table. The situation becomes worse, as already said, when both parents die.

If there is one dimension that PLWHA needs to look at very attentively is to develop a system where children can be protected in their environment by the extended families. We believe that African traditional solidarity is naturally a framework that can be exploited and encouraged by governments to take care of children who had lost their caregivers. In this regards, UNICEF believes that whenever possible, children who are orphaned should remain in their communities to be raised by their extended family. Recognizing that family care is far better for children and far less costly than institutionalized care, children who grow up in families also develop better social skills

and are psychologically better adjusted than those who grow up in institutions because they receive more affection and attention and develop a better sense of personal identity (www.unicef.org/aids/index_orphans.html). We totally agree with such an approach, which we believe should be given thought in Mozambique as well by PLWHA.

PLWHA Organizations and fund opportunities

PLWHA & Other Organisations

As already mentioned in chapter 1, the National Response to HIV/AIDS in Mozambique is positive. It passed through several stages. The National Control Programme against STD/AIDS (NACP) was created in 1988, and the first Medium Term Plan (MPT1) was developed. The NACP has a central body, located in the Ministry of Health, and regional offices in 11 provinces. The main responsibilities of the NACP include planning, coordinating, monitoring, and assessing provincial plans, and providing technical assistance to government sectors involved in the program. The NACP also develops short- and medium-term plans and establishes cooperation protocols for Mozambican and international NGOs, donors, and social, religious, and mass media associations. A second Medium Term Plan (MPTII) was developed in 1994. The National Strategy to combat STI/AIDS includes prevention, counselling, epidemiological surveillance, and blood testing. Specific components of the national program include management, information, education and communication (IEC), epidemiological surveillance, laboratory support, care of PLWHAs and counselling, and condom social marketing (Plano Estrategico Nacional).

Organizations in Mozambique such as (MONASO) brought together a variety of organizations working on HIV/AIDS activities throughout the country. MONASO's credit is to have prepared an organizational strategic plan to provide more effective coordination and assistance to local NGOs. With increased disclosure of HIV-positive status, a network of PLWHA has also been formed, and partnerships have been created between the network, other NGOs, and the government

Donors/Funding

Though PLWHA organizations are involved in counseling and psychosocial support, home-based care, training of members, education and awareness activities, these organizations still face various management problems including inadequate technical skills to run their organizations and difficulties in raising funds.

PLWHA in Mozambique have had access to financial supports over years that strengthen and support an expanded response aimed at preventing transmission of HIV, providing care and support, reducing the vulnerability of individuals and communities to HIV/AIDS. But most of the members of PLWHA associations when interviewed refer to finances as the major problem that causes troubles within the associations themselves and their relationships with other institutions. If we consider Elias argument when he says that

We got good relationships with the foreign NGOs; they give us money to develop our activities. The problem is that we don't get that money on time even after the contracts are signed. (Elias at Thinena association, Maputo: 2004).

Such a quote shows that not only these PLWHA associations had nowhere to turn to for assistance, but the PLWHA organizations are faced with organizational problems as well because many members do not have the necessary skills to run the organizations. They need to develop advocacy, fundraising and communication strategies to overcome these problems.

But before we go into all that, let us first remark that multilateral and bilateral donors are actively engaged in Mozambique. **UNAIDS** has a coordinating theme group based in Mozambique since the 1990s. The group, chaired by WHO, consists of representatives from UNDP, UNFPA, UNESCO, The World Bank, WHO, and UNICEF. In addition, major bilateral donors who provide the bulk of AIDS financing in Mozambique are active leaders of the group.

The World Bank supports HIV prevention as part of a road construction project. WHO is carrying out joint activities in the areas of epidemiological surveillance, STI and HIV/AIDS counselling, prevention interventions for vulnerable groups, and blood safety. WHO also provides some direct support to NGOs. UNDP is implementing a comprehensive national AIDS project. UNFPA will support improved integration of STI and HIV/AIDS services into existing reproductive health services in its country program from 1998 to the year 2000. Finland's Ministry for Foreign Affairs, Department of International Development Cooperation, supported a \$1.1 million community development project from 1995 to 1997. The project, implemented by The Red Cross of Mozambique, provided information about HIV/AIDS, nutrition, maternal health care, and hygiene, as well as blood transfusion services.

Pepfar (President's Emergency Plan for AIDS Relief), Mozambican government is now one of the recipients of US President George W Bush's \$15bn Emergency Plan for Aids Relief (Pepfar). But the beneficiaries of Pepfar cash are only allowed to buy drugs approved by the US Food and Drug Administration (FDA). This effectively rules out the vastly cheaper generic treatments that Ms Muhai benefited from. Orla Ryan (2004), BBC News business reporter in Mozambique says that Pepfar represents a healthy injection of cash into the fight against HIV/Aids. Just as importantly, it is the result of US recognition that action is urgently needed.

Private Voluntary Organizations (PVOs) and Nongovernmental Organizations (NGOs)

A number of PVOs implement activities in Mozambique, funded by multilateral and bilateral donors. Some of the major USAID cooperating agencies include The Futures Group, and Population Services International. According to UNAIDS, a relatively small number of NGOs are working on HIV/AIDS prevention and they are concentrated primarily in Maputo and other urban areas. The majority of NGOs receive their funding from external sources and work at a micro level, with limited impact on the epidemic at the national level.

These NGOs, however, do not assist financially unless the associations fulfill certain requirements. This is maybe what the adviser of Rensida (National Network of PLWHA associations) meant when he said that foreign NGOs and donor institutions are tough when it comes to financial support. They give money only when the project submitted to them fits their requirements. Sometimes this is not easy as the organisations have to adjust the project in such a way that it suits them in order to get money. So this kind of relationship is that of dependence. The organisation totally depends on those who have money to function.

This shows that the associations do not have a good dialogue with donors. The organisations have at all cost to accept their conditions simply because they have resources which we do not have. This situation has turned many people to deal with HIV issues depending on how able they are to plan or write a project and not out of real passion for HIV people. People in desperate need of income would go for project NGOs require in order to get finances (Motlhaolwa: 2001: 27-28).

Caution should be taken, however, not to generalize this situation because our research reveals that some international donor agencies are flexible and are willing to discuss and altering the implementation of projects presented by PLWA associations even if it does not fit their agendas.

Accountability is another problem that arises when dealing with financial support issues. In fact, most of these international NGOs demand the associations to give account of how the money given has been used. MONASO and RENSIDA are aware of this problem. Most PLWHA associations struggle with that problem. But it should be admitted that with good managerial skills, integrity, honesty and transparency this is not a big issue. There should be no fear of being accountable to somebody.

On the other hand members of the board of these associations manifest their disappointment in that even though they are given some money by their donors this money does not respond to the needs of the associations with its multitude of activities.

In response to this international NGO's and others institutions argue saying that PLWHA associations are not able to deal with big amounts of money due to the weakness that their administration presents. An officer points out

If they even have problem in justifying that small amount how can we trust them giving more money? (Officer of Action aid, Quelimane: 2004).

The officers are also reluctant as they believe that pumping in a lot of money for HIV/AIDS will not help as the money would be used for other purposes other than fighting against the pandemic. This is confirmed by Ivone who argues:

I don't think that all this money in Mozambique in name of HIV/AIDS is effectively used for the suffering people... there are so many organizations working in on this issue but why is it that the number of infected people increases daily? (Ivone , Maputo:2004).

In Chimoio a NPCS officer adds also that

Something has to be done in order to know really if what all these organizations say is true ... I started to organize the map with all details of each national and international organizations to find out what, where and how they operate in the field (Officer of NPCS, Chimoio: 2004).

As for the president of Thinena association in Maputo

The number of seminars and workshops run in this country and in the world if enough and if the money spent on HIV/AIDS was spent to a productive goal by then this disease could have been already minimized... (President of Thinena association, Maputo: 2004).

For him but the results in the fight against HIV in Mozambique are not satisfactory. According to the Strategic National plan with its new executive secretary it is important that the plan be shifted into another direction. He thinks that in the next few years to pay more attention to the suffering people mainly the orphans. It is in this regard that the CNSC has given more assistance to the orphan programs in the country nowadays.

Still on the front of funds for HIV/AIDS, others complain that they do not benefit from the few that come in for HIV/AIDS programs. The president of Thinena association in Maputo sadly remarks that

There is money for HIV/AIDS program in this country but we continue to die and suffer without food and unable to support our families... where does this money go? (President of Thinena association, Maputo: 2004).

This issue is very complex indeed. But despite all these disagreement between international NGOs and PLWHA associations and the members among themselves as regards funds, the activities of PLWHA cannot be undermined.

This section has shown how the epidemic has now advanced significantly in Mozambique, fuelled by labour migration, rapid urbanisation, high levels of poverty, insufficient health infrastructures and significant rates of sexually transmitted infections.

The Government of Mozambique has taken a robust stance, matched by significant international efforts to combat the epidemic. None of these have so far incorporated large-scale treatment programmes for people living with HIV/AIDS. The emphasis has been on prevention, awareness-raising, voluntary counselling and testing and palliative care.

The author looked at different institutions involved in this fight against the pandemic among which we have MONASO which is the AIDS-NGO umbrella organization funded in 1991. MONASO support the NACP in co-ordinating NGOs and CBOs working on HIV/AIDS activities. Nowadays hundreds of members are working under the guidance and support of MONASO in care and support, training of activists and peer-educators, PLWA, community mobilization, condom promotion and distribution. In each province there is a nucleus of MONASO. The most important activities carried out are: CBOs/NGOs mobilization – co-ordination and support, training for staff members, project design, Media and Government sensibilization and resource mobilization. An international NGO, PSI, is providing also technical assistance to the NACP through the implementation of a Condom Social Marketing (CSM) component.

Some private companies are participating with NGOs to facilitate IEC activities at the work place and are selling the NACP branded condom, JeitO. Around 1000 private sector commercial distributors of JeitO are currently throughout Mozambique. The World Bank & MONASO are in negotiation with many private companies for the obligatory inclusion of STD/AIDS prevention activities for the benefit of the project- workers (and communities surrounded) in the Roads and Coastal Shipping (ROCS) Project. In 1997, the UN Theme Group on HIV/AIDS has invited the chief editors of all major newspapers, radio and TV to discuss the possible roles of media in an effective AIDS program.

The Alliance has been working in Mozambique since 2001 and established a country office in 2003. It offers programmatic and organisational support to local non-governmental and community-based organisations, faith-based organisations, organisations of people living with HIV/AIDS and governmental institutions in the central provinces to respond effectively to HIV/AIDS. It enables orphans, vulnerable children and people living with HIV/AIDS to access quality care and support services through partner programmes in central Mozambique.

Mozambique is battling to contain HIV/AIDS and the government faces hard choices about funds that block access to the cheapest drugs. The Mozambican government is now one of the recipients of US President George W Bush's \$15bn Emergency Plan for AIDS. The fight against this pandemic still continues.

Having thus laid bare all these issues related to HIV in Mozambique, we now feel that the ground has been cleared enough for us to speak of the relevance of PLWHAs in Mozambique based on some history cases.

Relevance of PLWHA in Mozambique discussion

Relevance of the findings

This section is a summary of findings from the review of the author's experience on the work place and interviews with PLWHAs staff and members. Where appropriate, quotes from interviews and documents are included.

The author present first the findings related to the selected History cases's relevance, followed by PLWHAs intervention, their success and effectiveness. The report concludes with a summary of the lessons learned and considerations for the development of these associations up to 2005.

Before examining these history cases, it is important to signal that there are two views regarding the relevance of PLWHA associations: The first view is that these associations are very important because it is only through them that one is able to identify and bring HIV positive people together and assist them. Most HIV/AIDS positive people and national NGOs argue that when HIV people form (recognised) PLWHA associations, this prevents opportunists from getting money in the name people suffering from HIV/AIDS.

The second view, however, is that it does not matter whether there is an association or not because the members that are in the associations are less than the total number of people living with HIV in the country. In other words, not more than 1% of people with HIV/AIDS in the country are in these associations (INE, 2003). Therefore, people would like to see new ways of reaching HIV/AIDS infected people.

In Chimoio, a GTZ²⁰ official argues that:

'It is not important to have PLWHA associations in the country because of the financial costs which include both activities like capacity building and payments of staff members'.

She continues and argues that:

People in the board are the only ones who benefit in these associations and that many women do not see the benefits of being member of the association as they don't have key or high positions in these associations.

²⁰ GTZ it is a German Non Governmental Organization supported by the German government

Surprisingly enough the study shows the existence of GATVs in the cities even though more associations are being formed and expanding through the districts. Moreover, the testimonies of people living with the virus show clearly that these PLWHAs are of great impact in the lives of many Mozambicans if not all.

Presentation of some selected case histories

The focus here is on understanding the appropriateness and clarity of the goals and actions of PLWHAs in order to inform people about their effectiveness. The author analyzed these cases with the following questions in mind:

- Were the PLWHAs appropriate in terms of the needs and the expectations of the HIV/AIDS patients?
- Have they succeeded (at least morally) in assisting their patients?
- Were the planned goals, targets and outcomes clearly linked and comprehensive to people?

The following are some selected case stories of some HIV positive people in the associations. These stories can help us to better understand the problems faced by these people. This is to support the argument that people discover that they are HIV positive when they go to the hospital for other medical examination. Some extracts also elucidate the role played by the family in supporting their dear sick parent. Unfortunately there are examples that confirm that some times they hide their sero positive status prejudicing their partners. All in all situations, PLWHA associations helped these people in various ways to live with this disease without stress.

Case history 1²¹

Elisa aged 31, was divorced 6 years ago and is mother of two children. The oldest is 16 years, the second born is 13 years. The woman is educated up to grade 7. This woman was found at a support group called Tinhena at 1 de Maio hospital in Maputo. She told us her story:

I discovered that I was HIV/AIDS positive because from 2000, I was falling ill frequently. In 2002, I was diagnosed with Tuberculosis and the doctor advised me to undergo an HIV test because he suspected I was HIV positive. I went through the test and the results were HIV positive. I didn't believe the result and as soon as I started to feel better I dropped the treatment. A few months later, I got sick again. So I decided to resume treatment because I thought that I would die if I didn't take the treatment seriously. Now I'm feeling much better.

After getting divorced from her husband she started to work for a private newspaper as a cleaner to enable her support her children. When she fell ill she began to face problems with her employers. Her story continues:

[...] my doctor gave me a recommendation letter addressed to my office saying that I should avoid doing heavy jobs because of my illness. After presenting the letter, I lost my job, because my employers did not have light jobs for me and I was not given any terminal benefits. I took the matter to the Human Rights League of Mozambique. The case is still pending and I do not have any response yet.

I became sick two years after being divorced. I can say nothing about him. No one of my family knows about my situation. I'm afraid to tell them

²¹ For reasons of confidentiality, we will use pseudonyms (not real names) to refer to the people who gave us their testimonies.

because few months ago I lost my sister by the same disease, so I don't want to cause problems to my parents.

I live with my parents and my children. Before I lost my job, I used to help my parents with supporting the family from the little I had as a cleaner. They didn't know that I'm a HIV positive and when I fell sick I told them that I had tuberculosis.

I knew about the existence of this association for people living with HIV/AIDS group through that my late sister. I used to accompany her to this hospital and to this support group. In this support group we are all friends and we are treated in the same way

Case history 2

Jannet gives her own testimony in these terms:

I became sexually active when I was 15 year old. While I was a student I got pregnant and my partner organized the lobola.

When I got sick I was still living with my family and my husband. They took me to a traditional healer who told us that my illness was related to the payment of lobola. But since I didn't get better my husband's family took me back to my parents. Since that time, I never went back to my husband's place because he went to South Africa. But I knew that he was already sick before he left for South Africa. I am convinced having been contaminated by him. He was a polygamist with three wives including myself and had also many girlfriends.

None of us disclosed his/her HIV status to his/her partner, but I think that he started to undergo treatment and use to tell me that we will die together even if we separate from each other.

A few months ago I decided to tell my children that I am HIV positive. This was a way of warning them about the dangers of HIV/AIDS and preparing them to face the challenges of life when I will no more be there. I hope they got my message.

It is difficult for my father to look after us properly. At least he provides food and shelter. But I have to find ways to provide other things such as school fees for my children. I am now working as an activist for this support group. I hope we will have some incentive with time. Till now, we still struggle to find a financial support for our activities.

Case history 3

My name is Elisabeth aged 34 and mother of two children. The oldest is 16 and the youngest 14. I was married till my world was messed up in 98 when my husband died. When we got married, we were young and belonged to the same Christian church. We stayed together for 9 years and it was after that when my husband fell ill. I and his family thought it was a normal disease but he lost a lot of weight. When we took him to Machava hospital, he was found with tuberculosis and was admitted [Machava is a TB specialised hospital in Maputo]. When he felt better, he was discharged from the hospital and came back home. He discontinued his treatment and started drinking heavily. A few months later, he died. After my husband's death I also fell sick and was told at the hospital that I am HIV positive. Then I realised that my husband died from AIDS as well. Two years later, I had a boyfriend who was working in South Africa. I fell pregnant during the time I was there for visit. I thought of my HIV status and I realised that I had to make abortion. I asked my brother to assist me but he denied my request due to his religious belief. As a result my pregnancy grew up until I gave birth to premature twins but who eventually died.

Although I was ill during my pregnancy, my situation, however, became worse after I gave birth. I fell seriously ill, I had TB and herpes zoster. I went back to the hospital but the nurse was disappointed. She sadly remarked that I was not supposed to be pregnant knowing that I'm HIV positive. I apologised for my gaffe.

It was at the hospital where I found friends who introduced me to Tinhena association. I am now feeling better and taking the medication consistently. I love to be here because of the warmth atmosphere of friendship between us. I come here everyday. It is here where I find friends with whom we talk about our lives openly and support each other. We are comforted by the idea we have the same problem.

I am now living with the father of my late twins who also was tested HIV positive. I explained my status to him and he accepted to take an HIV test. We are living together without any problems. When I started the anti - retroviral treatment the nurse asked me to come with a family member. I took my father. (This is a condition for starting this kind of treatment in all hospitals). My husband's father helps us to support the family because both of us are not working.

Some of my family members know my HIV status but I have never told others about it.

While this story seems to have a happy ending, not all of them do.

Case history 4

My name is Jorge. I am 34 years age and have never been married but I used to have a lot of girlfriends. I stay with my brother, my sister-in-law and my nephews. My brother is the only one who is working. It was in 2000 that I started feeling that I was sick. While ago in South Africa I used to work as a security guard in a company in Gemirsten and had that privilege of going to the hospital for treatment. Despite these good efforts, instead of improving my condition was worsening. This is how I ended up loosing my job and was given money, just enough, to travel back home. In Maputo my family took me to traditional healer in Gaza province but there is no improvement.

The first and serious disease I suffered from in my life was a sexually transmitted disease. The hospitals in South Africa failed to solve

this illness. When my brother took me to the hospital I already had a lot of complications. Besides, I developed herpes zoster and lost a lot of weight. I was unable to move by my self.

I was asked by a medical doctor to undergo an HIV test and the result was positive. I was admitted and transferred to hospital “1 de Maio”. Before I started with my treatment, I was already left with 34kgs only. What a loss! I was put on an anti retroviral treatment which I have continued to take till now. Nevertheless, I regained weight and weight 68kgs now. I know for sure that HIV/AIDS is real. I have this disease because of having many girlfriends, many sexual partners. I was never concerned about safe sex. I trusted all of them, I never used condoms. See what happened now!

I was invited by the coordinator of the support group to attend the meeting after consultation with the doctor, and I joined this group. I learned quickly that that I was not the only person on earth with this problem. This is how I started attending meetings every week. Now I also invite other people to join our group.

No one in my family knows that I am HIV positive apart from my brother who took me to the hospital, therefore, I have never been discriminated against by any of my family members or neighbour what ever.

As activists we have a project to visit fellow HIV positive people at home, we are not receiving any incentive but we hope that we will start receiving that very soon. If we had some incentive, that would be good for us, we would be able to look after our families and continue to work without worries.

Discussion of Findings (case histories)

These examples of case histories are what one should consider as revealing the reality of HIV/AIDS in Mozambique. These examples also may put to rest any argument that PLWHAs are not doing a proper job in Mozambique. They prove beyond any doubt that

PLWAs associations give real support to HIV positive people in this country. These case histories, moreover, represent and continue to represent several cases of HIV peoples bad and good experiences all over the country.

In the first interview (and many others that come after) Elisa shows how she only went for an HIV test when she realised that she was seriously sick. Like her in Mozambique most people realise that they are HIV/AIDS positive only when they frequently fall ill and are advised to take an HIV test. Based on our interviews 100% of people in the associations knew about their situation because of the persistent illness. The author is, therefore, tempted to generalise that people in this country never decide to have HIV test before they can experience illness. Yet having HIV test before one is seriously sick can increase chances for one to protect himself. Researchers suggest that the proper strategy for battling AIDS is to attack the virus. Most researchers, however, believe that the best approach is to treat HIV early, since this may preserve the body's own defenses against HIV.

Reading Jannet's story in interview 2 makes the author at first glance to think of polygamy as one of the main causes of HIV infection in Mozambique. In Mozambique, HIV infection increases because husbands who usually have a number of sexual partners. It is often to hear of stories like this by Stephanie Nolen (2005) about Azarias Mateusse and his four wives. *It has been four years since they buried Azarias Mateusse in the crowded cemetery in Xai Xai, but his shadow still looms large over the little concrete house where he lived with his wives. His first wife, Anita Manhiça, 43, is rail-thin and racked by a bone-shaking cough. These days she lies on a straw mat in the dusty yard, with barely the strength to tug a faded cotton sheet around her shoulders. She shivers, although it is 30 C. Azarias's second wife, Alba Houhou, 31, is starting to feel unwell. Some days she hardly has the energy to get dressed. She sends the children to fetch water from the village standpipe. And his third wife, Gracinda Invane, 33, has read the signs at Azarias's house; she has taken her two children and moved into town. But Gracinda, too, most likely has AIDS.*

Jannett is one of those victims in a polygamous marriage, whose marriage makes her end up HIV positive. Polygamy is the most frequent and main mode of transmission of HIV. Most HIV positive persons in this country have up to four partners (if not wives).

Another issue is that Jannett has been able to reveal her HIV status to her kids. In fact, deciding who to share your status with not only is a very personal decision but also a very difficult one to take. It may be hard to know if telling certain people will bring good or bad consequences. You might fear negative responses like rejection, discrimination, abandonment, or isolation. You might worry about being judged or feel guilty about past drug use or sexual behavior. In some situations, revealing your status could put you at risk for physical harm. Since some people may not be as accepting of your HIV status, these are all valid issues to think about.

Telling kids about one's status is not a practice which is common in Mozambique where it can be associated with taboo. If you have kids, telling them about your HIV status can be even more challenging. It is like telling them about other touchy topics -- such as body parts, puberty, and sex issues. But telling them can sometimes be rewarding.

Because on the Children with infected parents are a growing group who have concerns of their own: "Who will take care of me if my parents get sick? What happens to me if they die?" So, it might help them to start imagining their own destiny in this world without parents. But this depends on age since the youngest ones (0 to 10 year old) have nothing to do for themselves.

The National Women's Health Information Center (2005) writing about *Women and HIV/AIDS* acknowledges that there are mixed opinions on how mothers should handle this difficult decision. It provides however the results of some studies which show that open communication about the illness to their kids is better than not telling them. Children may already know something is wrong; keeping the illness a secret can confuse children and make them feel anxious. Other studies, the center argues, have found that children have negative reactions to being told, like behavior problems, sexual risk-taking behavior, and lower school performance. Several studies have shown that if a HIV+

mother reveals her status, telling a child to keep her health condition a secret is stressful for that child and as a result, that child may have behavior problems.

In one study, women with HIV who told their children about their illness were interviewed. They recommended these tips for talking to your kids about your HIV status.

- Think about why you want to tell your children. Make sure you're ready.
- Educate yourself about HIV so you can talk to your children about the illness.
- Plan for what you're going to say.
- Consider how healthy you are. It might be better to talk to your child when you're feeling healthy and can show your child a healthy, positive attitude.
- Think about other things going on in the family. It may not be the best time to tell your child when there are other stresses in the family.
- After you tell your children, get them additional support. They could talk to a health professional who can talk more with your children about HIV.

With regards to the above, we see that it took Jannett a lot of courage to reveal her status to her kids. It is left to the reader to see where, when, how, why, and whether or not do the same once found in the same circumstances.

The author is provided with other encouraging issues by *Elisabeth Ricardo* in interview 3 whereby the speaker who supposedly contaminated her husband with the virus encourages him to confirm it with a test and the later surrenders. The author is also encouraged by the example given by both families supporting them even as *Elisabeth* started her antiretroviral treatment.

Unlike most cases where they have portrayed women as sexual objects by African men, here *Elisabeth's* example forces us to believe that African men are not all unreasonable. An HIV positive man can also make his partner understand that although she might be

the cause of his misery but he does not blame her for his own mistake for having not undergone with her for test before marriage. This makes the author also to believe that all the myths, stereotypes around African men being abusive can be challenged though still happening here and there. Gender equality has been firmly on the transformation agenda in Africa. Values such as respect of women's dignity and opinions are now recognized and getting ground.

Family support as, already discussed, is very important for HIV positive persons. *Elisabeth* example is of many which show that African people are good in providing practical and emotional support to their family members in pain no matter how the disease was contracted. (e.g. individuals living with HIV or AIDS). What they need maybe is a frame where a range of special services or training to those affected by their loved ones having HIV or AIDS so that they can now what exactly to do when the subjects undergo treatment, how to handle them.

In Interview 4 *Jorge* goes for traditional leaders to cure HIV/AIDS. It was also observed that some of the respondents consulted traditional healers at the same time that they are undergoing treatment in their respective hospitals. It is still believed by some people in Africa that HIV is caused by witchcraft or sorcery therefore *Sangomas* (traditional healers) or traditional healers are the only ones who can handle or solve such problems. This is easily rejected by science which believes that HIV disease has nothing to do with spirits intervention and therefore see it as a merely body disease. Whether this African belief is based on metaphysical dimension is a result of their ignorance or not, it remains, however, true that some people confess openly that traditional treatment is worth it.

AIDS action (2004) argues that 'western' or 'modern' medicine can reduce levels of HIV in the body and treat HIV-related opportunistic infections, but many people with HIV have no access to even the most basic western medicines. It is estimated that in many developing countries, particularly in rural areas, four out of every five people visit traditional health practitioners and use traditional treatments.

Traditional healers already treat large numbers of people living with HIV and AIDS. It is important to look at approaches to working with traditional health practitioners that can

improve HIV prevention and care services, while continuing to advocate for improved access to western medicines and treatment.

Some programs have trained traditional health practitioners in HIV/AIDS and other sexually transmitted infections (STIs). Appropriate training encourages traditional health practitioners to replace harmful practices or myths about HIV with safer practices. It can also help them to diagnose HIV and other STIs and encourage increased collaboration with biomedical or 'western' health services. This collaboration can have a number of advantages and biomedical health practitioners also need education in the benefits of working with recognized traditional health practitioners. For example, traditional health practitioners often have an approach to healing that takes into account the whole person - their mental, emotional, spiritual and physical health. Initial research into a variety of traditional treatments also suggests that some of these treatments offer potential relief from HIV-related infections; although like western medicine, none of these treatments is a cure for HIV.

This issue proper referring of *AIDS Action* looks at some successful approaches to working with traditional health practitioners and using traditional health practices to improve HIV prevention and care.

The traditional healers should be perceived as educators. This is so because respected traditional health practitioners see many clients and they can be very powerful educators. They have influence in the community, as well as with other healers through their professional networks. They understand local belief systems and can explain illness and misfortune in ways that people understand. It is important that they have correct information about HIV/AIDS and other sexually transmitted infections.

This paper argues that many people with HIV approach traditional healers even when they have access to other health services. One reason is that traditional healers usually treat the 'whole' person, not just the disease. They take into account a person's mental, emotional and spiritual as well as physical well-being. This can include contacting the spirits for help.

Traditional health practitioners often see their patients together with other family members and can play an important role in family counseling and in reducing stigma and discrimination against people with HIV/AIDS.

A quick look at these stories also revealed that what most of them share in common is that they often fail to disclose their HIV status (except to one case story). Most of the people interviewed confirmed that they did not tell any one of their family members that they were HIV positive until they started taking ARVs. This problem is related to discrimination and stigma. Similarly all complain about poverty and being unable to look after their family.

Finally, they all acknowledge the help they got from the support group or PLWHA associations. This frame provides a contact point and meeting place where HIV people get together and talk through their thoughts, fears, worries and frustrations without being faced with the stigma associated with the illness.

In short, people living with HIV/AIDS (PLWAs) can live positively with HIV longer if they talk openly about their problems and share information with others. Keeping HIV a secret could make those who are infected feel unhappy and stressed. Such emotional stress weakens the immune system. Disclosing (sharing) one's HIV status with someone else can help people get counseling, and help them get connected with others who are HIV-positive and able to provide support. In addition to people with HIV attempting to talk more freely, the entire community and religious leaders can contribute to the fight against HIV/AIDS by avoiding stigmatizing those with HIV and cooperating with each other to address the problem.

Conclusion

In this chapter the author has shown how HIV organizations have developed from support groups into associations. This was out of the need of becoming formally structured, be legally recognised by the ministry of justice and also to reach more people. It was believed that only associations could achieve these goals. The feelings, sentiments and desires of HIV people or PLWHAs members, their struggles and happiness in life both as individuals and members of PLWHAs were clearly expressed and presented in

this chapter. Most importantly, among their problems lays their need of being accepted in the society. The social responses of fear, denial, stigma and discrimination which have accompanied the epidemic for a while need to be dealt with. HIV people should not be denied access to the services and treatment they need. In Mozambique where HIV and AIDS are believed to bring shame upon the family or community, we insisted that good policy or law should help combat HIV/AIDS related discrimination.

Gender inequality was raised as one of the main cultural issues related to HIV in African and particularly in Mozambique. In this chapter, the have provided an overview of the gender-based abuses in this country that fuel the HIV/AIDS epidemic and make the lives of women and girls already living with HIV/AIDS unbearable. The argument was based largely on the horrifying stories told by women and girls who have suffered abuse from their husbands and in-laws. Through stories and voices of the women and girls and through research, the report illustrates the inter-linkages between human rights violations of women and girls and the HIV/AIDS crisis. It is hoped that an understanding of the human reality of these abuses will lead to greater protection of the rights of the girls and women at the center of a deadly epidemic.

The also spoke about fund raising. PLWHAs struggle to have funds though some efforts made by donors such as World Bank and others to support them. In fact, the author recommend that those HIV organizations (PLWHAs) that are serious about fund raising must also be committed to developing a rapport and reaching out to potential donors. Building relationships with donors, potential donors, local community and local government are essential. The more these organizations are kept informed, the higher the chances are that they will continue their support. The author also suggested that honest communication between the organizations and the donor can improve the lives of the sick people.

The author ended this chapter with case histories where analysis was made on some testimonies of HIV +people. It has been observed that people living with HIV/AIDS (PLWAs) can live positively with HIV longer if they talk openly about their problems

and share information with others. Keeping HIV a secret could make those who are infected feel unhappy and stressed.

CHAPTER 6 - CONCLUSION

Recapitulation of key issues

HIV/AIDS is a new holocaust that reaches all people independently of race, religious, sex, age or social position. The consequences of HIV/AIDS can be far-reaching for young people. Not only does HIV disease have terrible consequences for the individual, causing serious illness and eventual death, it has the potential to trigger negative social reactions. Across the world, people with HIV/AIDS routinely experience discrimination, stigmatization and ostracization.

The intrinsic problems posed by this pandemic constitute a new challenge. The increasing number of people infected by HIV/AIDS in the world has forced the infected people to be organized in groups or associations in order to face together the challenges of living with HIV/AIDS in the society.

The associations of PLWA and its members face many problems such as discrimination and stigma that is attached to the scourge. But notwithstanding these problems, these associations are showing an incredible dedication to addressing the issue of HIV/AIDS.

In Mozambique, the associations have specific and unique problems that are linked to the realities of the continent. These problems include poverty, illiteracy, cultural stereotype and many more. Despite the fact that many associations, in Mozambique as in other parts of Africa, are experiencing difficulties; some associations have done very well in their work. For example, the South African and Ugandan associations have so far demonstrated that they are capable of defending the interests of their members. For Mozambique, however, there seem to be no definite improvement to HIV/AIDS issues in Mozambique despite the good work which is undergoing there under the PLWHAs. The legal future of this population is unpredictable, it is less certain, but the author believes that, at least for the therapeutic aspect, a big part of HIV population, efficient comfort from these PLWHAs associations has been obtained.

In the three provinces where this research was conducted evidence revealed that the associations of PLWHA are a new phenomenon, where the members are looking for their own space in order to tackle the problem that is being posed by HIV/AIDS.

This research tried to disaggregate the experiences that are pertinent to these associations and give a voice to people in these associations. Most of the time, matters of HIV/AIDS have been ranked as least priority. This investigation of PLWHA associations which was conducted in three different geographical areas in the country showed more similarities than differences. These differences and similarities were within the association itself, the day to day running of the association, and the relationship of these associations with government institutions and civil society.

The study found three major modes of heterosexual transmission, transfusion and mother to child. The risk factors are: poverty, migration (miner), population movements, refugee return from countries with high HIV prevalence, high prevalence of STD in young people, resistance to condom use, economic dependence of women, and also lack of information, illiteracy and disbelief.

The research reveals, furthermore, that there are no significant differences between HIV/AIDS associations in these three provinces. There are more similarities than there are differences. They share in common unemployment, low level of schooling, uncontrolled urbanization, prostitution, lack of resources to support their family members, etc.). Other types of similarities are shaped by patterns of formation of these associations which were similar and may have been formed by the same people. However, in Maputo which is the capital city, due to the favourable conditions there, these associations and support groups are more developed and dynamic than in other provinces. It would however be interesting to find out how HIV/AIDS positive people in rural areas are responding to the problem of HIV/AIDS.

It is also worth remarking that HIV geographic distribution is uneven in the country. Central provinces (Manica, Tete, Sofala, and Zambezia) are more affected than the Northern and the Southern Provinces. The trends follow the major transport routes and the areas bordering Zimbabwe, Malawi and Zambia. In these areas of the country, many

factors, in the past, have contributed to increase HIV/AIDS infection and other are fuelling the spread of the epidemic (unemployment, low level of schooling, uncontrolled urbanization, prostitution, e.g.).

The study also found much variation or inequality between men and women around the issue of sexuality displayed by gender roles. For women and adolescent girls, the consequence of AIDS can be particularly dire. There is strong evidence, for example, that in African countries (e.g. Mozambique) women are often "blamed" for HIV disease even in circumstances where they have been infected by remaining faithful to their husband or other male partner. There is also evidence to suggest that women are less likely to receive the kind of care and support made available to male household members (Warwick et al., 1998). Moreover, where the male head of household has died there is sometimes loss of social support for young women, ostracization from the community, and lack of legal protection to inherit land and property.

The gender inequality is mainly confirmed by the reaction of men towards HIV test. It is said that when a woman is diagnosed with HIV/AIDS first, she does not get support from the husband or his family because the tendency is to blame her for contracting the disease and she may end up being returned to her parents. On the contrary, if the disease is detected first in the man, the wife will normally support him till his death even though she may be accused by her husband's family of bewitching the husband.

This study found that HIV positive women face difficulties when it comes to following the teachings of vertical transmission programmes because they lack the capacity to feed their babies with artificial milk. They feel obligated to breast feed their children because their families expect them to do so. In this regard, women are faced with difficult decision of disclosing their HIV status. On one hand, if they disclose their status they face the risk of being chased from home and, on the other hand, they face the risk of transmitting the virus to the baby if they breastfeed their child.

In Mozambique there are two different types of associations of people dealing with the problem of HIV/AIDS. These include support groups and PLWHA local association. Support groups are the informal groups that are not legally recognized by the Ministry of

Justice, while PLWHA associations are formal organizations and are legally recognized by the government. Nonetheless the objectives and most important activities are the same in both forms of organization. Most members joined the associations and support groups after being invited by the other members working as activists in hospitals.

This research argues, however, that lack of adequate knowledge about HIV/AIDS, fear of infection, the stigmatization, put these associations at a disadvantage in coming out to speak about their HIV/AIDS status and its associated problems.

This research accepts also the fact that members in these associations are firstly concerned with gaining material and financial support although sharing experiences and mutual consolation among members remain the ultimate goals. Most members of these associations are people who have HIV and are who lack economic means to have a better living. Therefore they are weak and have problems with performing their jobs.

The income-generating activities run by these associations are not sustainable because of stiff competition. There are too many NGOs doing the same income, generating activities making it too hard to market products produced. Another weakness is that they lack initiatives and the capacity to negotiate with donors for long term sustainable project.

The context of poverty, dependence, superstition, illiteracy, unemployment, violence and an overall sense of doom plays a role in sexuality and sexual and interplay amongst the poor, shaping their responses and, as shown in this thesis, their inability to protect themselves in the face of this pandemic. This highlights the fact that HIV/AIDS is a different reality for the rich and the poor people. In this regard, poor people in these associations do not have the means to support themselves and their families, while rich people have means to themselves and their families and can afford treatment in private clinics.

In Mozambique prominent citizens living with HIV keep their status hidden and are not involved in HIV/AIDS information awareness campaign in the associations of PLWA. This could be because of the fact that HIV/AIDS is seen as a disease for poor people. The

stigmatization of HIV/AIDS has become so high that people infected with the disease deny any association with this epidemic.

It was also realized that rich people experienced confidentiality with issues relating to HIV/AIDS when compared to poor people. This is because while poor people have to go the associations to deal with his/her reality, rich people have options of private clinics.

It should be added that poor members of PLWHA associations regard themselves as near death since they do not have access to antiretroviral drugs and other resources. They believe that their way of life changes after being diagnosed HIV positive they feel discriminated against and alienated by their families and their communities.

It was also discovered that most members of the associations did not disclose their HIV/AIDS status to their partners and families. They behaved as though they are not HIV positive and continued to have many partners. Women continue their reproductive cycles and breastfeeding despite attending the PTV Programa de Transmissao Vertical 'Transmitted Vertical Program' where they are through how to avoid the vertical transmission. The reason behind is that the fame of having a baby or being called mother of *xx* or *xy* (baby's name) is in Africa much more valued (even if the baby eventually dies later) rather than not having one.

This study showed that there are more women than men in PLWHA associations because women are found to have HIV/AIDS virus when they attend consultation related to their reproductive health. Women in these associations normally do not assume high positions and therefore it is difficult for them to address their major concerns. Men usually occupy executive positions. The traditional attitudes of gender inequality which consist in men always occupying dominant positions are reflected in the associations.

The research also showed that family members bear the burden of caring for the sick and their dependants and have the potential to do so even though they are sometimes failed by their limited resources. When a family member is HIV positive, it entails a high burden on his family because they have to support him/her under high level of poverty, increasing unemployment, deterioration of household income, and rising cost of living,

and poor coverage of health services. But there is sometimes little involvement of family members in the activities of PLWA associations due to lack of information. And some get interested only when their family members are about to start ARV treatment as required by PLWHA. Before a patient begins with his/her ARV treatment, a member of the family has to be briefed on the consequences of undertaking this treatment.

It is sad to remark that the increasing number of *GATVs* in the country is not accompanied by increasing level of knowledge of the HIV/AIDS pandemic. The number of people who undertake voluntary testing for HIV/AIDS is insignificant. Moreover, the only service provided is HIV/AIDS testing for people suspected of having the virus by the hospital.

Mozambique is passing through a difficult time in that beside the HIV/AIDS pandemic, the Government has to deal with other national issues which divert government attention on the problem of HIV/AIDS. In addition to the above, the adoption of the new liberal policy to reduce the intervention of the state in social welfare, health, and education impacts negatively on the fight against HIV/AIDS. Nonetheless the government does intervene on a small scale through the CNCS and the Ministry of Health. This is illustrated by increasing number of *GATVs*. The approval of antiretroviral policy is a good example of the interventions of government although many people also die from the treatment's side effects.

These findings revealed that the relationship within associations and between the various stakeholders is not always harmonious. Weak partnership among NGOs working in the field of HIV/AIDS, competitions for funding, and disagreements among the members of these associations are some of the problems that hinder the successful implementation of HIV/AIDS programmes. Most of the associations acknowledge that their organisations are weak and that; they lack human and financial resources to efficiently and effectively implement programmes. However the National networks of HIV/AIDS has made efforts in trying to solve this common problem jointly in the last few years.

Recommendations

On basis of the findings of this research, the author would like to make the following recommendations:

Given the fact that less than 1 % of People Living with HIV/AIDS in Mozambique are members of these associations, there is a need to do more work to integrate more people in these associations by mobilising people under VCT and, if they are found HIV positive, to encourage them to have access to associations, or perhaps even compel them to join as a condition for receiving ARV treatment.

HIV health care services and activities of PLWHA association should be extended to people affected with HIV/AIDS in the rural areas.

Government, civil society and the media should step up its efforts of reducing discrimination and stigmatization of PLWA through information campaigns. They should also redesign the messages in the information campaigns to ensure that they reach achieve the targeted audience, and add messages that promote PLWA associations and the benefits of joining them.

It is important to have a national welfare policy which will mitigate the problems of people infected and affected by HIV/AIDS. Particular attention should be paid to vulnerable groups like children who have been orphaned as a result of losing parents through HIV/AIDS. The government should take the responsibility of supporting HIV/AIDS positive women by providing milk and other food for their babies until they have grown up. Above all, reducing poverty should be one of the effective ways to deal with HIV/AIDS.

Prominent citizens in Mozambique should be mobilized to take an active role in the fight against HIV/AIDS. If they are infected they must come in the open and declare their status and get actively involved in the associations of people living with HIV/Aids in Mozambique. By doing this they will change the mentality of poor people who view AIDS as a disease for poor people.

NGOs and CBOs should strengthen their internal organizational structures and broaden their networks through forming partnership with other NGOs dealing with this issue. The increased efficiency in terms of service delivery and partnerships will strengthen their collective voice and make it easier for them to share resources, to work with other non-NGOs actors, and to lobby with the Ministry of Health Ministry and other institutions.

The author would like to call upon the government of Mozambique to increasingly involve PLWA in responding to the HIV/AIDS pandemic.

The government in conjunction with other stakeholders involved in the fight against HIV/AIDS should come up with a strategy that will encourage its citizen to undergo routine voluntary testing and counseling for HIV.

Government in conjunction with other stakeholders involved in the fight against HIV/AIDS should be more efficient and effective, thereby reducing the negative effects of bureaucracy. The government should mobilize more resources so that all HIV/AIDS infected people may have access to ARVs.

Given the challenges of the HIV/AIDS epidemic, the government and civil society need to pay attention to the plight of these families who usually have limited resources and are faced with the task of dealing with this problem.

The challenge of associations in Mozambique, therefore, is to recognize these weaknesses and to find means and strategies for overcoming them in order to reduce the impact of HIV/AIDS in the country.

Significance of Findings

These findings have significance for the discipline (anthropology) because they show that although much progress has been made to integrate HIV issues into our discipline, but much more still needs to be done. As a whole, anthropologists need to work much more effectively to produce, and publish more about HIV/AIDS. The findings also illustrate great differences between the creation and maintenance of PLWHA associations. There is a great discontentment from the members as regards to the management as they believe

that those in positions of power misuse the money. This money does not profit everybody. The author is of the opinion that this claim is worth consideration and that those engaged in business of HIV organizations need, and would consistently be, more concerned about the well-being of those whose rights and needs they claim to defend. A 'poor' quality service hosted by a business such as this one can generate immediate negative feedback from HIV people. If these poor people continue to express their dissatisfaction with services offered they may feel penalize both sides by the disease on the one hand and mentally and emotionally on the other hand.

Limitations and Future Research Opportunities

This study has hinted at a number of research areas which merit further study. In the area of retroviral treatment, it would be helpful for there to be an ongoing effort to evaluate whether this treatment helps or does not help Mozambicans. Researchers need to see on a continuing basis the side effects of these drugs. Another issue is that of structures that need to be put in place for HIV children or orphans left behind by parents who died with HIV to grow from with family love.

The idea of extended family that needs to be supported financially as they might wish to foster these children is a great idea but which requires further investigation. We think that PLWHA need to include such a project in its program as well. Surely there will be improvements and even greater improvements in the future if this project is given thought.

There should be additional research work to compare the PLWHAs operational, and informational enhancements of HIV education programs in urban areas with those operated by these organizations in the rural areas. The lack of knowledge or information in these rural areas demands it. Yet, the current research has illustrated areas in which the PLWHAs services are more advanced although it did not cover the whole country. Perhaps additional research work with larger populations would help in this regard.

There is clear evidence that PLWHA well-designed programs of sex education, which include messages about safer sex as well as those about abstinence, may delay the onset of sexual activity, and reduce the number of sexual partners, and increase contraceptive

use among those who are already sexually active). Here again, further ongoing research is warranted to see to what extent sex education's applications are important for HIV positive and negative people.

The current research has barely scratched the surface of what is obviously a concern of many international donor Institutions and NGOs. A reading of the written survey responses by our interviewees shows that there are clearly many financial problems related to mismanagement of PLWHAs or lack of transparency as far as the funds are concerned. A clear relationship has already been established between PLWHAs and their international donors on HIV issues; they must continue to build this relationship (foundation) so that it can save the lives of millions of people hit by the virus. How can the structure be altered as to meet the objects originally designed for the associations? This is the question that must constantly be asked and addressed to the stakeholders and more especially the leaders of the PLWHAs.

All these issues are important in a general sense in that their investigation will help us better explain our world and the people living with the virus. But the issues are critical to the future survival of the PLWHAs associations, which have themselves been threatened in many ways in the recent past. If we are to be the true researchers that Africa needs, we can possibly be in the research effort we make along these lines that must continue and be able to create effective strategies now to fight against HIV/aids in the years to come.

In short, the research effort was limited initially by a lack of theoretical development in the literature. Previous works did not provide enough linking materials on HIV to The case study of PLWHA, its creation and maintenance of its programs as evidenced by the interviews. While the methods used here are reliable, and the means of measurement appear valid, the concepts involved have not previously been investigated elsewhere and should be subject to further study.

This research was not intended to make claims about discussing the entirety of all the problems pertaining to HIV disease. Rather, the research was aimed at making generalizations about HIV as dealt with by PLWA associations in Mozambique, how they help those who are infected and affected by HIV. This research supports the work

that PLWHAs association do save lives of people. Whether PLWHAs have succeeded or not is another issue and the reader may draw his/her conclusions from the work.

Recommendation for further research

It could be important to find out how other HIV/AIDS positive people out of the associations follow the life of these associations. The institutions dealing with this issue have to investigate how they can work with other informal associations based in the communities and religions. To extend the study at level of rural areas, as a way to explore what the local institutions do in this context. Why these associations are only concentrated in the cities? As we live in the time where people migrate from rural areas to big cities in search of better opportunities of life will not be the cities invaded once more by HIV if considerable efforts are not made to contain the disease both in the cities and rural areas? Further studies are needed to explore all these areas. Above all as Monteiro suggest is important to accept the perceptions of multi voices approach in this matter of HIV/AIDS in Mozambique.

This study revealed that a number of significant socio- cultural factors had an impact on HIV/AIDS situation in the three provinces. But it didn't gather evidence showing how these different factors impact in HIV/AIDS context. For instance data from INS Instituto Nacional de Estatistica ' National Institute of statistic' concerning to HIV/AIDS prevalence in the three regions of the country, indicate that the Northern Region has a low level of prevalence. It may be important to undertake a study in this region where Muslims are predominant.

It would also be interesting to find out why other HIV/AIDS positive people are not members of these associations dealing with the problem informally and not through associations, for example at household level, community level, church level etc.

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<http://www.napwa.org.au>

Appendix

(1) List of Acronyms and Abbreviations

AIDS- Acquired Immune Deficiency Syndrome

AMODEFA- Associacao Mocambicana do Desenvolvimento da Familia

CBOs- Community Base Organizations

CEA-UEM- Centro de Estudos Mocambicanos Universidade Eduardo Mondlane

CNCS- Conselho Nacional de Combate ao SIDA

FDA- Food and Drug Administration

FDC- Foundation for Development of the Community

Frelimo- Front of National Liberation Movement

GATV- Services of Counseling and Voluntary Testing

GTZ- German Technical Cooperation

HIV- Human Immunodeficiency Virus

ICW- International Community of Women Living with HIV/AIDS

INE- National Institut of Statistic

Kindlimuka- A National Organization of People Living with HIV/AIDS

MISAU- Mozambican Ministry of Health

MONASO- Mozambican Network of AIDS Service Organization

MPT1- Medium Term Plan

MSF- Medicos sem Fronteiras

MULEIDE- Mulher Lei e Desenvolvimento

NACP- National AIDS Control Program

NAPWA- National Association of People with AIDS in South Africa

NGOs Non Governmental Organizations

NPCS- Provincial Nucleon Against AIDS

PLWHA- People Living With HIV/AIDS

PLWA- People Living with AIDS

PMA- World program for Food

PNUD- Programa das Nacoes Unidas para o Desenvolvimento

PVOs- Private Voluntary Organizations

RENAMO- Movement of National Resistance

RENSIDA- National Network of Associations of People Living with HIV/AIDS in Mozambique

SAT- Southern Africa AIDS Training

SIDA- AIDS

STI- Sexual Transmitted Disease

TARV- Ante Retroviral Therapy

TASO- The AIDS Support Organization in Uganda

UNAIDS- United Nations Agency for AIDS

UNDP- United National Development Progr am

UNDP- United Nations for Development program

UNICEF- United Nations Children's Fund

USAID- United States Agency for International Development

VTC- voluntary Counseling and Testing

WHO- World Health Organization

WLWA- Women Living with AIDS

Guide of the interviews for the different target group

Specific questions directed to members of the board of the associations

Here major emphasis was put on understanding the many issues that can be divided into 3 sections, as follows:

- What has motivated the creation of the associations? Who, how and when they were created?
- How do they do function?
- What type of structure do they have?

The way members adhere to the associations as well as the membership requirements; member's rights (benefits) and obligations; their funding sources; the way associations interact,

Both in the country and outside.

- Difficulties encountered (relationship among members and with other members of the civil society, governmental institutions and financial support).

PLWHA who are members of the associations

Concerning this target group, it's maybe also important to find out what actually motivates people to join those associations.

- In what circumstances and how do they learn about the association's existence and mission?
- Why do people become member?
- What are the advantages and disadvantages in being a member of such kind of association?

- Do they receive some kind of advice?
- Are their family members aware of their individual membership status towards the associations?
- How do their family and other members of society in general react to this situation?

Officers of the local and international NGO's dealing directly with these associations:

- When did they start working jointly with these associations?
- What kind of partnership do they develop with these associations?
- Do they develop specific activities? What kind?
- What are their impressions about PLWHA's associations?
- What are their major difficulties in dealing with the associations?
- Apart from these associations, which other partners do they have?
- What are the differences between the associations?

Governmental institution's representatives working with the associations

It is perhaps important to get to know the government's position towards matters related to People Living with HIV/AIDS in the country, because they are the most important decision-making bodies. It seems also relevant to find out the kind of strategies they draw on in dealing with the HIV/AIDS pandemic, particularly with people already suffering from AIDS. Questions including:

- What kind of support do they give to the associations?

- What are the challenges being taken by the government towards minimizing the impact of the disease?

What type of activities do they develop in these contexts?

**A Comparative Study of Associations of People Living
With HIV/AIDS in Mozambique: The case of Maputo,
Manica and Zambezia provinces**

Elisa Maria da Silveira Muianga

A dissertation Submitted at School of Social Anthropology, University of Witwatersrand,
Johannesburg, in Partial Fulfillment of the Requirements for the Degree of Masters of
Humanities and Social Sciences, Department of Anthropology

Johannesburg, 2005

Declaration

This thesis is entirely my own work and has not been previously submitted as a research project, dissertation, or thesis, at any other University

.....

Elisa Maria da Silveira Muianga

January 2006

University of the Witwatersrand

Dedication

To my children Neusa Tania da Silveira Chitsonzo and Ivan Maximiano da Silveira Chitsonzo and my parents.

Acknowledgements

I would like to thank to my supervisor Prof. Robert Thornton for his guidance during the elaboration of this thesis.

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Deep thanks go to Rensida staff, PLWA Associations (in Maputo, Chimoio and Quelimane), MONASO, CNCS, FDC, Hospital Dia and others in (Maputo, Chimoio and Quelimane) for providing me helpful information for this study.

Thanks to all members of the different associations of PLWA in Mozambique especially those located where I carried out the study in Maputo, Manica and Zambezia province.

I would like to thank Kellogg's Foundation and AED for the scholarship and research fund that made it possible for me to realize this thesis. I could not be happy without addressing my thanks to CEA/UEM, the institution that gave me the opportunity to continue with my studies.

Abstract

This study was inspired by the need to develop awareness about what is going on in Mozambique regarding to the issue of HIV/AIDS. The research examined how and why the organizations of PLWA (People Living with HIV/AIDS) in Mozambique are emerging and developing, compared the particularities of the existing organizations of people living with HIV/AIDS in three province of this country (Maputo, Manica and Zambezia), and finally examined how they function, and interact with governmental and non- governmental institutions.

The study made use of the ethnographic method to design and generate a rapid "picture" of the social culture around this HIV community. The focus on this method provided further in-depth qualitative insights. Behavioral surveys were designed to provide rapid key data on sexual behavior, condom use and STI¹s. Together, these sources of data provided a spatial, quantitative and qualitative overview of the research.

The results from this study turned that the associations of PLWA and its members face many problems such as discrimination and stigma that is attached to the scourge. But notwithstanding these problems, these associations are showing an incredible dedication to addressing the issue of HIV/AIDS.

In the three provinces where this research was conducted it transpired that the associations of PLWHA are a new phenomenon, where the members are looking for their own space in order to tackle the problem that is being posed by HIV/AIDS.

The research reveals, furthermore, that there are no significant differences between HIV/AIDS associations in these three provinces. There are more similarities than there are differences. The associations have in common issues such as unemployment, low level of schooling, uncontrolled urbanization, prostitution, lack of resources to support their family members, etc. Other types of similarities are shaped by patterns of formation

¹ Sexual transmitted infections

of these associations which were similar, what invites one to think that may have been formed by the same people.

As combating HIV/AIDS seems an important tool in poverty eradication, Government, civil society and the media should step up its efforts of reducing discrimination and stigmatization of PLWA through information campaigns. They should also redesign the messages in the information campaigns to ensure that they achieve the targeted audience, and add messages that promote PLWA associations and the benefits of joining them.

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CHAPTER 1 - Scope of the Research

HIV 'community'

Our world today is one in which organizations are designed and created as tools that help those living with HIV/AIDS. It is one of the greatest challenges for our times. The fact that biomedicine has not been able to come up with a cure for AIDS has aggravated the association of this disease with stigma, discrimination, denial, shame, fear, silence and death.

HIV/AIDS: Acquired Immune Deficiency Syndrome (AIDS) is the result of an infection with the Human Immunodeficiency Virus (HIV). This virus attacks selected cells of the immune, nervous, and other systems impairing their proper function.

According to UNDP every 6 seconds, someone becomes HIV positive. The increasing number of people infected daily by HIV/AIDS in the world has, on the other hand, pushed people organize themselves and put into place existing structures to help to some extent people living with HIV/AIDS. (PNUD: 2004)

Mozambique has one of the highest HIV positive rates in the world. About 16, 2% of the adult population (15-49 years) is estimated to be HIV positive. There are about 500 new infections per day. About one million of people are HIV positive (MISAU: 2005).

This constitutes a large HIV community, that like others communities such as ethnic, economic, religious, found reasons to organize themselves to respond their eminent needs.

In this study, the term 'community' means first 'HIV community'; and being a member of it has different meanings in a practical sense to different people. To some it means people living with the virus, to others it means all those who are interested in HIV issues, while to others it means organizations such as PLWHAs.

PLWHAs understand their membership in terms of rendering specific services to the community or giving financial, moral or intellectual support.

Aims of the research

The aim of this thesis is to examine how and why the organizations of PLWA in Mozambique are emerging and developing, compares the particularities of the existing organizations of people living with HIV/AIDS in three province of this country (Maputo, Manica and Zambezia), and understand how they function and interact with the governmental and non- governmental institutions. The present study also seeks to document the impact of the disease on people relationships, by looking at how the subjects of the study interact with other socio-cultural organizations such as families in their lives. Another important aim of the study is to map the experiences of the associations in the three provinces studied, as a way to understand the subjects' experiences (those living with HIV-AIDS into the associations) in Mozambique.

In short, this thesis seeks to show how the subjects of the study battle with HIV and difficulties inherent in this struggle through the associations that support them. It is in this context that author seeks to give voice to those people who have been marginalized by their HIV status and stigmatization.

Research questions

In support of the research aims formulated in the paragraph 1.2, the following research questions will be researched.

- How and why the organizations of PLWA in Mozambique are emerging and developing?
- What are the similarities and differences among organizations of people living with HIV/AIDS in the provinces of this Maputo, Manica and Zambezia?
- How do these organizations function and interact with the governmental and non-governmental institutions?

- What is the impact of HIV/AIDS on people relationships, concerning to how the subjects of the study interact with other socio-cultural organizations such as families in their lives?
- What are the experiences of the associations in the three provinces studied, concerning to dealing with people living with HIV-AIDS in Mozambique?
- How do the subjects of the study battle with HIV and difficulties inherent in this struggle through the associations that support them?

Benefits

If readers and researchers explore the nature of research questions fully:

- The research project has more chance of fitting in smoothly with the plans of this association;
- Other associations and researchers are likely to learn from the process as well as the outcomes of research projects; and
- These associations, the government and researchers will be able to consider the implications of research for practice over a longer period.

Theoretical Framework

The topic of this thesis concerns organizations of people living with HIV/AIDS in Mozambique. This topic could be viewed within the framework of “civil society” which could be complemented by the others concepts such as social movements. Considering that this study was been done in Mozambique where the PLWA associations fall in the category of NGOs, the concept of NGOs will be also discussed.

Controversially, it has been observed that there are several conceptual definitions of civil society. Which entities what should be considered as civil society and its relation to the state? This concept is contested. Social scientists too have a problem defining civil

society in a precise and concise manner. The concept has attracted different perception and meaning. In other words, there is no consensus on the exact meaning of the term. In this study the Kaviraj's definition can fit well, when he argues that civil society is "an organized institution standing outside the state's legal *jurisdiction*, which undertakes and finds a response to specific matters within the social, political economic domains". (Kaviraj *et al*, 2001). In this perspective, different kinds of organized groups of people such as associations can fall in this category.

This concept of civil society can be reinforced by embracing the another key concept, that of Social Movement, understood as a collective action, made by an informal group(s) of people of different social categories usually excluded from history who begin asserting themselves as historical actors. Normally they are committed to broad change at the levels of individual behavior, social institutions and structures. Examples include social movements of women, ecologists, gays and others which have played a role played in social and political changes through the world.

In this regard the HIV/AIDS community can be seen in the category of excluded group considering the deep stigma and discrimination associated with this disease.

Altman argues that according to the level of organizations and commitment these movements can achieve important goals. He took the example of a gay movement that managed to influence governments and the society to develop a sense of identity among its members. (Altman, 1989:30).

The organizations of PLWHA in Mozambique can be regarded as a way of responding to specific matters of concern in the world by a group of NGOs (NGO is an acronym for non-governmental organizations that cover a whole range of organizations from e.g. small local environmental pressure groups to large international human rights organizations).

- They must be non-violent groups.
- They must not want to replace the incumbent government- they should not be political parties or opposition groups.

- They should support the aims of the organizations which recognize them (Berg, 1998: 12).

The movements of civil society play an important role in the fight against HIV/AIDS. However, attention should be given to the fact that a civil society is not above in this battle. In Uganda, for instance, they work side by side with governmental institutions. The country's authority calls for full involvement of CBOs, NGOs, donors and religious institutions (Thornton, 2003a; 2003b).

Controversially, in South Africa, the civil society, in the context of HIV/AIDS, appears to be an opposition force to the government, and puts pressure on the government to force it to pay more attention to this concern. In Mozambique civil society pleads with the government and complements the work of the government.

Using this theoretical framework, I will analyze, examine and assess their effectiveness of the role of these organizations in the context of Mozambican civil society.

Given the wide spread of HIV/AIDS in the world, and Africa in particular, the number of organizations dealing with this pandemic especially associations of people living with HIV/AIDS is increasing everyday.

This phenomenon, which opens ways for '*groups directly affected to organize themselves*' (Goss *et al*, 1995: 6), can in some way be justified by the relatively limited government intervention. The UN's secretary general, Kofi Anan assumed this same position during an interview with the BBC News answering to the question on whether he was winning the battle against HIV/AIDS, his response was that: "*I am not winning the war because I don't think the leaders of the world are engaged enough*" (in <http://www.news.bbc.co.uk/2/hit/Africa/3244564>).).

People living with HIV/AIDS seek to organize themselves in associations as a way of sharing their difficulties, fighting against common enemies, giving each other emotional and spiritual support and practical assistance (Kaleeba *et al*, 2000). That is why the author personally found it important to undertake this study and see to what extend the existing three associations of PLWHA in Mozambique follow the objectives above.

Mozambique has got three PLWHA organizations so far. In mid 1990's the first one was created in Maputo city. A few years later, two other associations emerged in Chimoio city (Manica province bordering with Zimbabwe and in Quelimane city (the Zambezia central province), respectively (MONASO²: 1999). These associations operate only in the province's capital cities.

As a Mozambican, I have interest in undertaking this case study because in Mozambique, according to available reports, stands among the sub-Saharan countries with the highest number of people infected by HIV/AIDS. However, the number of associations of people living with this infection in the country is assumed to be far less than expected; in addition to this, most people likely prefer not to adhere to those associations, or even to be aware of the advantages of being a member. The fear of being discriminated and stigmatized by the society could be the most important reason.

This study will assess the importance of these organizations dealing with PLWHA.

Methods and techniques

This study was undertaken following a *qualitative ethnographic methodology*. This methodology was adopted because the study is an exploratory study. It examined specific sites, comparing small groups in order to bring out perceptions of the people involved in these organizations and their major concerns, such as:

- The people's motivations for creating the organizations of PLWHA in Mozambique
- The functioning or organizational structure PLWHA organizations
- The organizations funding sources, and
- Their major constraints

² MONASO is a network of HIV/AIDS organizations in Mozambique. It incorporates all sorts of organizations dealing with HIV/AIDS.

The study brings together the perceptions of the people involved in these organizations and their major concerns.

This research was conducted in Maputo, Chimoio and Quelimane cities in Maputo, Manica and Zambezia provinces respectively. It is in these three provinces where the first associations of people living with HIV/AIDS PLWHA were located. This specific task was to observe the way associations interact in their respective offices and/or clinics. It also gave the opportunity to look at the ways they deal with their members including their common problems.

Along side this method the research also includes the combination *semi-structured, open-ended interviews*. *Semi structured interviews* were administered to the board members of local and international NGOs as well as government institutions. *Open -ended interviews* for members of the associations and *case studies* were also recorded from some people living with HIV/AIDS in the associations.

Participant observation during fieldwork was the principal method for data collection. In short, a *multimodal approach* was an effective strategy towards strengthening the sources' reliability.

Fieldwork and procedures

The first step of the fieldwork was to make arrangements with the umbrella institutions based in Maputo which directly deal with associations of PLWHA at national level. In this way, four institutions were first contacted:

1. Rensida *Rede Nacional de Pessoas Vivendo com SIDA*, an umbrella organization that is working with associations of PLWHA.
2. MONASO, 'Mozambican Network of AIDS Service Organization' that includes national and international NGOs dealing with HIV/AIDS issues.

3. CNCS, *Conselho Nacional de Combate ao SIDA*, 'National Council on the Fight against HIV/AIDS' is a governmental institution which coordinates all activities related to HIV/AIDS at all governmental, civil society and private sector levels.
4. Ministry of Health which supervises all issues related to public health including the HIV/AIDS pandemic.

This strategy enabled me to have a picture of what these associations have been doing in the context of HIV/AIDS in Mozambique on the one hand, and to make arrangement for later contact from there with the associations and others institutions targeted for this research, on the other hand.

After this step I came to the second step of *in-depth interviews*. In Maputo I interviewed a number of the governmental institutions such as Ministry of Health, Ministry of Woman and Coordination of Welfare, Hospital dia and CNCS. All these institutions were also contacted at provincial level. All interviews were taped for transcription.

In the process, I also dealt with NGOs both national and international. One or two officers from each of them were contacted. The selection was done according to the level of involvement in HIV/AIDS issues. From HIV associations, however, I interviewed two staff members, the president or the executive director or secretary, or both of them, depending on their availability. In the provinces five members of the same associations who were targeted responded as well to the requests. The number of National and international NGOs in each province varied from one province to another. The majority of them were contacted whenever they were referred to the author by others during our interviews.

It is important to observe that this study was possible only in the capital cities of the provinces for the simple reason that the districts do not have associations of people living with HIV.

In Maputo were in total 25 interviews with HIV-AIDS positive effective members of the associations including case histories of NGOs, national and international, and five governmental institutions. Similarly, in Quelimane two interviews were conducted with

HIV associations, ten HIV positive members belonging to both existent associations. Three International and three National NGOs were contacted as well as the three most important governmental institutions at provincial level: Health, Women and coordination of Welfare and CNCS National Council on the Fight against HIV/AIDS.

In Chimoio were contacted two associations made up of twelve members, six in each association. Two international and three national NGOs were contacted. The same governmental institutions contacted in Quelimane were also visited and contacted in Chimoio.

Given the nature of the study, it was not easy for some people to respond to the interviews for fear of discrimination and stigmatization. In Maputo, for example, in one of the support group I was asked to reveal my sero status – to determine whether I was like them, since this would make them comfortable during the interview. Skhosana confirms how difficult is to conduct study in this perspective. According to her, she found specific strategies in that moment to deal with her research (Skhosana: 2001)

In Manica province I was asked by two young people to be paid for having been interviewed. It has been a practice for some researchers to pay the interviewees. However I did not pay informants for information.

Special problems arose during the fieldwork in all studied provinces when some associations (i.e. members of the board) of HIV people were the ones who decided which people should be interviewed and which not. Without their mobilization it was not possible for me to find people for those interviews.

All in all, the fieldwork covered a period of three months. It should be acknowledged that all was done successfully but not without some obstructions. I quickly learned an important lesson that a researcher even in her own country should not assume that the interviews will be transparent and unproblematic. As a field worker I was, also able to learn more than the scope of the research itself. I was able to notice laughter, reprimand, correction through which I had to see how people living with HIV socialize or fail to socialize with others.

Constraints

Language or communication barrier was one of the difficulties I had in the field, but not a major one. In cities where most people speak Portuguese, I chose Portuguese as a language for communication. However, some HIV positive were more confident speaking in their native languages, I solved the problems through interpreters.

Photographs were taken to document some findings and they added support to the data collected. Verbal consent of participants was sought before photographs were taken. Some of the informants did not allow pictures, fearing that I could sell their images.

Ethical considerations

Given its delicacy, this research topic has a lot to do with informant's intimate life and privacy. Interviews were conducted in a careful manner, following the principles of respect and confidentiality according to the WITS University's statement of principles and the American Anthropological Association's statement of Ethical principles for Anthropology. I made our informants aware of the research's purpose, which is to seek and contribute to further improvement of the associations of PLWHV and their memberships and obtained verbal or implicit consent. In learning about others through active participation in all steps of my fieldwork, I learned for example, in this context of HIV, those who were suffering from it, I tried by all means to make them feel free and more comfortable despite their status. I also protected their identity as professionally required for an anthropologist researcher. In short, respect and confidentiality were the most important requirements considered during the fieldwork.

Structure of the work

In **Chapter I** of this work, a brief overview of the topic is outlined. The Introduction identifies also the scope of the study of PLWHA 'People Living with AIDS'. The concept of civil society and social movements are discussed. The principal techniques used in the research, are described.

Chapter II gives a broad picture of HIV/AIDS in Mozambique. After years of colonial rule, civil war, floods and famine, Mozambique is now considered one of the world's poorest countries with one of the highest HIV infection rates – 13.6% of 15-49 year olds are HIV positive. This chapter gives a picture of PLWHA organizations in fighting against HIV/AIDS and helping HIV people.

The literature review is the main concern of **Chapter III**. This section provides the sources cited throughout the work. It offers information on the range of other studies cited and how they influence this work. I include work of scientists in other disciplines, such as bio-medical, psychology, and culture. The literature cited in this section shows how HIV/AIDS issue is the concern of everybody and not just anthropologists.

Chapter IV is about presentation of the three provinces in study. The general idea of these provinces related to the location in the country as well as the population is given. Some socio- economic indicators are shown in the context of specificities of each provinces. Factors that would influence the prevalence of HIV/AIDS are presented. On the end there is presented the PLWA organizations in each province and a brief history of their creation and function.

Chapter V deals with the presentation and analysis of results. This results section contains the **data** collected during experimentation. It is the heart of this paper. In this section, much of the important information is in the form of translated interviews. Tables and graphs of characterization of members of the associations of PLWA are also given.

The **Conclusion VI** re-states clearly and concisely the key issues covered in each of the main points in the body of the text, and provide a concluding statement that integrates the ideas presented there.

CHAPTER 2- BACKGROUND INFORMATION ON HIV/AIDS IN MOZAMBIQUE

Country profile



Mozambique



Fig. 1 Map of Mozambique country
([http // www.worldpress.org/ profiles/ Mozambique](http://www.worldpress.org/profiles/Mozambique))

The population of this country is approximately 18 million people where more than 99% belong to indigenous ethnic groups. The ratio of men to women is 96 to 100. Forty-two percent of the population is under the age of 15. (INE: 2000)

Mozambique is considered one of the world's poorest countries, and all of the country's social indicators are well below sub-Saharan African averages. Mozambique's ten-year civil war reversed post independence improvements in basic services and had a major impact on mortality and morbidity, especially among children. Thirty to forty percent of Mozambique's children are chronically malnourished. Roughly 60 percent of the population still lack access to health services. The Mozambican government now allocates 8 percent of its current budget—about US\$2 per person per year—to the health sector. (INE: 2000)

During most of the civil war, the government was unable to exercise effective control outside of urban areas, many of which were cut off from the capital. An estimated 1 million Mozambicans perished during the civil war, 1.7 million took refuge in neighboring states, and several million more were internally displaced. In the third FRELIMO party congress in 1983, President Samora Machel conceded the failure of socialism and the need for major political and economic reforms.

In December 2004, Mozambique underwent a delicate transition as Joaquim Chissano stepped down after 18 years in office. His newly elected successor, Armando Emilio Guebuza, has promised to continue the sound economic policies that have encouraged foreign investment.

Part of the poor conditions in Mozambique is a heritage of Portuguese colonization, because under this regime, educational opportunities for black Mozambicans were limited, and 93% of that population was illiterate. In fact, most of today's political leaders were educated in missionary schools. After independence, the government placed a high priority on expanding education, which reduced the illiteracy rate to about two-thirds as

primary school enrollment increased. Unfortunately, in recent years school construction and teacher training enrollments have not kept up with population increases. With post-war enrollments reaching all-time highs, the quality of education has suffered. However this has improved after independence (Serra: 2000).

HIV/AIDS in Mozambique

HIV/AIDS is one of the greatest threats to the development of Mozambique, kills people in their productive and reproductive years. This pandemic has a responsibility to increase the vulnerability of the families associated with the increasing of numbers of orphans in the country. Health and education services are losing skilled staff, reducing the provision of these services.

According to the MISAU, Ministry of Health and the INE the epidemic situation of HIV/AIDS in Mozambique by province and by the three regions in 2002

Province of Mozambique	Prevalence %	Prevalence %/ Region
Niassa	11.1%	8.4% North region
Cabo Delgado	7.5%	
Nampula	8.1%	
Sofala	26%	16.7% Center region
Manica ³	19%	
Tete	14.2%	
Zambezia	12.5%	
Maputo city	17.3%	14.8% South region
Maputo province	17.4%	
Gaza	16.4%	
Inhambane	8.6%	
Mozambique	13.4%	
Mozambique actually	16.2%	

Table 1 HIV Prevalence by Province. Source: MISAU: 2002 and 2005

According to MISAU pointed that in 2001 about 56.600 adult people have died by AIDS
Concerning the life expectation according to the projection, in 1999 it was 43 years; 2004 46.4 years and in 2010 could be 50.3 years without AIDS. However the life expectation

³ The provinces in red are that in study

with AIDS in Mozambique at the same periods was 41 years; 38 1 years and will be 35.9 years with AIDS, respectively. (MISAU: 2005).

For the surprise of Mozambican the recent data of Ministry of Health indicate that the current national prevalence 2005 is 16.2 %. Half of the people living with HIV/AIDS (PLWHA) in Mozambique are between the ages of 15 and 29. Girls and women are at especially high risk and are being infected at a ratio of two to one over men. In 2004 we had 470,000 orphans due to HIV/AIDS in Mozambique. Currently, we have more than this figure, which will increase to over one million orphans by 2010. (MISAU: 2005). Extreme poverty, urban and cross-border migration, unequal distribution of power between men and women, stigma, and low literacy levels fuel the HIV/AIDS epidemic.

The first AIDS case was reported in Mozambique in 1986. The country's HIV prevalence rate is lower than the rates of neighboring Zimbabwe, Zambia and Malawi, largely due to the isolating effects of the civil war.

The scale and future impact of HIV/AIDS in Mozambique can only be understood by examining it in relation to its young population. Youth, aged 10-24, comprise 34% of Mozambique's population, and youth aged 15-24 account for 60% of new HIV infections in a country estimated to have a HIV prevalence rate of over 12% (MISAU:2005) .

Although the isolating effects of a ten-year civil war kept the HIV prevalence rate in Mozambique lower than the rates in neighboring countries, it is still one of the nine countries in Africa hardest hit by the epidemic: Given the increasing number of people suffering from HIV/AIDS the Mozambican government has approved antiretroviral therapy (ATR) and diagnostics policy in the country. But the costs due to the rising number of persons living with HI/AIDS will overwhelm an already existent health care budget. Prevention activities focused on young people, the mobile population, better quality and coverage of voluntary counseling and testing services. The actual cost of ARV treatment per patient is 250 USD per year what means that the government has to expend too much money only for this matter while malaria tuberculosis, cholera continue to kill more than AIDS (CNCS: 2005)

In short, Mozambique is a country where people have seen all. The Mozambique Liberation Front, or Frelimo, formed in 1962 by Eduardo Mondlane, Frelimo sought to completely liberate the country from Portuguese rule. The war lasted over 10 years, effectively ending in 1974 when the fascist regime was overthrown. The independent Republic of Mozambique was proclaimed on 25 June 1975:

Then troubles really began. The drought and famine of 1983 also brought the country to its knees. In January 2001, floods killed about 700 people, left half a million homeless and devastated the economy. Some of the flooded areas - and many others besides - were then hit by a drought the following year. The economy remained crippled by debt, with annual payments almost twice the public health budget. Above and overall the country is fighting against HIV/AIDS today.

NGOs and HIV/AIDS in Mozambique

The NGO sector in most countries like Mozambique led the early responses to HIV/AIDS issue. There are many different typologies and classifications of these NGOs. However we can distinguish two: national and foreigner NGOs that specifically dealing with AIDS called by AIDS services. Normally these organizations are members of MONASO and RENSIDA national umbrellas of organizations dealing with HIV/AIDS and of PLWA respectively. Since the end of decade 80 local NGOs of PLWA started emerging and integrating these two umbrellas.

These organizations in general focus their activities mainly on the following areas:

- Prevention of sexually transmitted diseases and of HIV/AIDS transmission among young people through school awareness programmes;
- Fight against discrimination, stigmatisation and marginalisation of people affected by and infected with HIV/AIDS;
- Support of families caring for relatives living with HIV/AIDS;
- Care for children orphaned by HIV/AIDS.

- Advocacy for ARV treatment
- Few of them in partnership with the government provide ARV treatment

The increasing number of PLWA members enlarged the “HIV community” that wanted to organize themselves. Similarly, the increasing disclosure of HIV- positive status has led to the formation a national network of PLWHA, as already indicated in the introduction, which works in partnership with other organizations and the government. The RENSIDA (National Network of People Living with HIV/AIDS was created in 2000.

In this Network are included PLWA but mostly who are member of HIV/AIDS associations. The most important aim of this National network is to stimulate the formation of self-help groups of local People Living with HIV/AIDS, to coordinate and support their activities, and to help bring them together in one voice. This network for PLWHA receives financial support from SAT, UNICEF, Action Aid and ONUSIDA (interview with secretary of Rensida ,2004: Maputo)

The association known as *Kindlimuka* ‘wake up’ in the local Ronga language is the oldest of the PLWHA organizations in Mozambique, founded in 1996. Based on Kindlimuka’s experience, thirteen other associations of PLWHA have been established in others provinces. The formation of these associations is behind National and Inetrnational NGOs as well as governmental institutions such as services of blood and GATVs. (services of counseling and voluntary test)

These associations have as main tasks:

- Providing counseling, home -based care and inc ome generation activities including the production and sale of clothing and material for construction.
- Organizing education on how to prevent HIV/AIDS for young people aged 13-18 years in schools. Testimonials by association members on their sero-status have become an effective tool used to reduce stigma and to increase awareness.

- Identifying vulnerable children and families caring for orphans, with involvement of community leaders.

RENSIDA is an umbrella organization. It is a Non-Governmental Organization, which integrates all organizations of People Living with HIV/AIDS in Mozambique. Activities implemented by RENSIDA with the UNICEF complement each other. UNICEF has been supporting institutional capacity building of RENSIDA through technical advice, training, and the provision of material and equipment. RENSIDA developed a national strategic plan and operational plans of the associations in 11 provinces for 2004. In addition, UNICEF has been supporting community monitoring projects for orphaned and vulnerable Children through RENSIDA in fifteen districts in Gaza (Kuvumbana), Manica, Sofala, Tete and Zambézia provinces

CHAPTER 3 - LITERATURE REVIEW

HIV/AIDS as a social phenomenon

Today, as in the past, those who write about the issue of HIV/AIDS emphasize the role of people living with HIV as infectors rather than those who are infected to such an extent that this view is widely accepted as "common sense." In public health initiatives, the "public" appears not to be concerned about how to help these people who contracted HIV to live a better life of stigma, rejection and marginalization, and also help them not to disseminate or transmit the virus to others – innocent people and children considered to be potentially innocent victims of AIDS, at the expense of others like prostitutes. But, in so doing, writers promote oppression of HIV positive people and impede the struggle against HIV.

The first cases of HIV/AIDS in the world were associated to the homosexual people and drug users so people in the heterosexual life were not concerned about this disease.

Today many people blame prostitutes or sex workers. Generally, women and men working in the sex trade have been considered as vectors for transmission rather than persons who, for many reasons, including legal reasons, are vulnerable to contracting HIV. But most recently, the evidences show that every one is susceptible to be HIV positive independently of their sexual orientation. Related to HIV/AIDS indicators in Africa, are handicapped by inadequate means of confirming diagnosis, on the other hand the high sickness rates contribute in a large way to obscuring the true prevalence of HIV/AIDS in many African countries (Agadzi, 1989: 92). HIV/AIDS cannot be seen anymore as only a bio-medical disease. "Specific social and cultural patterns such as the sexual networks, the availability of needles, the political and economic power relationship of prostitution, the nature of transport routes areas of high prevalence are factors showing the social face of this disease" (Altman, 1994).

As Altman remarks that no illness in human history has generated so many meetings, so many scientific publications, nor so much political rhetoric and government response Altman, 1994:2) as HIV/AIDS. In fact, a number of articles trace the history of

HIV/AIDS (Altman, 1994; Macks, 1987; McAdam, 1996; Agadzi, 1989; Corr, 1994; Cad & E, 2002). Though different resources have been consulted in the frame of this research, this work, however, has heavily drawn on the research conducted by Altman's *Power and Community: Organizational and Cultural Responses to AIDS*, 1994 that discusses various HIV/AIDS organizations. It shows how other forms of responses to HIV did not successfully help those who live with the virus and how, most striking of all has been the response from those most affected by the epidemic itself. It strengthens the idea that without strong community-based responses the best meaning of public health systems will fail to deal with the crisis of AIDS. For Altman "one of the major goals of the community-based movement has been to slowly drag public officials to recognition of the multi-faceted needs of an appropriate HIV/AIDS strategy.

HIV/AIDS and vulnerability of poor people

Altman recognizes that the HIV spread and its social consequences are closely linked to the dislocations of economic and social 'development' and, in West, to the growth of particular sub-cultures and regimes of sexuality. In other words, a single approach the study of this pandemic cannot help; it needs to be approached from various angles, including cultural and economic aspects. According to PNUD (2004) 39.4 million people are estimated to be living with HIV 25.4 millions can be find in Sub Saharan Africa. The increasing number of people with AIDS in Africa mainly in Southern Africa, for example, allows us to associate this disease with poverty. Obviously, the people of this region are most frequently infected because of their life conditions (Altman: 1994).

Lancet (2004) in Preventing HIV/AIDS through poverty reduction remarks that the association of poverty with increased HIV prevalence does not necessarily indicate a causal relation. But for him, explanations have been offered at several levels as to how poverty may increase susceptibility to HIV/AIDS. He has also argued that poverty increases biological susceptibility to HIV/AIDS in the same way it does many other infectious diseases. When he refers to the malnutrition, parasitosis, and lack of access to health care among the poor, suggests that these factors undermine the integrity and immunity, and increase the likelihood of having other

untreated sexually transmitted infections. All of these influences can increase susceptibility to HIV infection and progression.

Of significance in this debate is also the fact that poverty is not alone in its destruction. It is also often associated with lack of education, and illiteracy can mean that messages regarding risk and prevention are inaccessible. These authors continue to argue that even with knowledge of the risks; the cost of prevention may be prohibitively high because many poor people are unable to afford condoms. Poverty also restricts people's choices and leaves few options but to undertake high risk behaviors. It is in this context that in Lancet (2004) also identified poverty-driven labor migration and commercial sex work as activities likely to increase HIV infection.

Thus, poverty is one important factor in increasing susceptibility to HIV/AIDS, and facilitating its spread. HIV/AIDS also increases poverty, at all levels from individual to nation, through its impact on working age populations. The morbidity and mortality among this age group affects household incomes, and is a major challenge to the ability to deliver services such as education. It is important to recognize, however, that there are many other influences besides poverty acting to facilitate the spread of HIV/AIDS. Income and gender inequalities are likely to be as important as absolute poverty, as shown by the high prevalence of HIV/AIDS in countries with large inequalities. Other challenges include finding the political will to combat the epidemic, and the stigma associated with HIV/AIDS.

With respect to this debate two conclusions to be drawn from the above observations. First, since poverty plays a role in creating an environment in which individuals are particularly susceptible and vulnerable to HIV/AIDS, poverty reduction will undoubtedly be at the core of a sustainable solution to HIV/AIDS. Therefore, investment in equitable poverty reduction efforts must continue, even in the face of other pressing needs. Second, since poverty is clearly not the only factor contributing to the spread of HIV/AIDS, there is no excuse for taking a fatalistic attitude to the epidemic, in which little can be done until some utopian poverty-free ideal has been achieved. We can concur with Lancet, and others that social factors such as poverty, gender inequality and illiteracy

are closely related to HIV/AIDS increase and need to be studied deeply, reduced if we have to succeed in our fight against HIV in Africa and Mozambique in particular.

There are more studies relating HIV/AIDS to poverty specifically on household of developing countries. Desmond and Gow advance the view that the capacity of vulnerable household and communities to respond to the economic, social, and health impact of HIV/AIDS on their households are weakened ever day due to extreme poverty. women and children are the most seriously affected “ that is why anthropology has the methodological tools to study the social experiences of those who are afflicted by this disease while simultaneously keeping the humanity of those who are infected in the professional discourse on AIDS” (Desmond & Gow, 2002:19).

HIV/AIDS pandemic as already stated above required the involvement of community-based organizations because other groups which existed before these did not include those most affected by the epidemic. In Latin America people place stress on the concept of civil society and the need to strengthen it. In this work the stress is on the civil society which we believe can help organizations of people living with HI/AIDS such as PLWHA. Like Altman, we believe that the importance of intellectuals in the largest sense may help communities make sense of meanings of AIDS. Hence the emphasis on anthropological intervention in this research which puts high demands on social and cultural aspects of HIV/AIDS.

Countrywide organizations of PLWA

National Networks of People Living with HIV/AIDS worldwide are becoming more and more powerful acting on behalf of all people living with HIV/AIDS. The oldest national AIDS network organization in the world was found in the USA, in 1983. According to NAPWA, too little attention has been paid to the very real issue of meeting the prevention needs of people living with HIV/AIDS. The best strategies for preventing new HIV/AIDS infections should engage people with HIV/AIDS as partners, but it is also important to consider that people living with HIV/AIDS are extremely heterogeneous, and programs need to address the different needs of such a diverse group: Race, gender, sexual orientation, age, language, geography etc.

People Living with HIV/AIDS in the world are been organized themselves as a way to respond the epidemic rather than being blamed for the epidemic or regarded simply as its unfortunate victims. So HIV positive people have been valued as one of the society's most important assets in coping with the effects of the pandemic and preventing its further spread.

The global Network of PLWHA is a world network for and by people with HIV/AIDS. It is based in Amsterdam, Netherlands, and has a board of 12 members representing the various international regions. The overall aim of GNP is to work towards improving the quality of life of people living with HIV/AIDS. This can be achieved through the capacity building of people with HIV/AIDS.

According to Williams (1995), PLWHA associations in general, have the following objectives: (1) psychological care, (2) emotional support, (3) medical treatment and nursing, (4) information, (5) material assistance, (6) acceptance and non-discrimination. As mentioned above, the association's primary objective is to support people living with HIV/AIDS and their family members. It could be in terms of moral or economic support. Some of them provide community and home care assistance. Their membership is mostly impoverished people, thus limiting their capacity and effectiveness in advocacy. This also reflects the existing social stigmatization against them from the moment they reveal to be HIV positive or AIDS patient. This is a real situation in Mozambique. In different parts of the world, for instance in Uganda where HIV/AIDS awareness is high and greatly supported by the civil society, there are national networks of this kind of associations.

The examples of Uganda and South Africa

Organizations of PLWHA worldwide enface the problem of discrimination and stigma, but given the increasing number of infected people and this kind of associations they are fighting these issues with a relative success. This has proved true in Uganda through the TASO Organization of People Living with HIV/AIDS and NEPWA National Association of People Living with HIV/AIDS in South Africa where they have been extremely important in shaping their society's response to HIV/AIDS.

In fact, Uganda's response to HIV/AIDS has been comprehensive therefore is seen as a model for the rest of Sub-Saharan Africa. Since 1992 HIV prevalence in Uganda has dropped by more than 50%. The involvement of government institutions, the civil society as well as numerous community led initiatives could be the most important factors for decreasing HIV/AIDS in this country.

(www.cdc.gov/nchstp/od/gap/country/uganda.htm)

Organizations like TASO (The AIDS Support Organization) and Phill Lutaya initiatives strive to put a "*human face to HIV/AIDS*". So ordinary citizens associated AIDS with real people then their own risk perception increased and turn were more receptive to campaigns for safer sex. (www.aidsugand.org/pdf/role-of_vct.pdf)

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In different parts of the world, for instance in Uganda where HIV/AIDS awareness is high and greatly supported by the civil society where are included private sector and organizations, churches and denominational associations, self-employed workers co-operatives and unions, and NGOs to face this pandemic.

Authors like Fieldman and Carter add that successful battle against HIV/AIDS in Uganda can be also associated to the government policy strategy consisted in empowering women giving them the voice in first person. On the other the encouragement to bring out people in good status to talk about their sero positive status was helpful to combat the stigma. (Fielman & Carter, 2003).

NAPWA's international programs works to combat the HIV/AIDS epidemic by advocating for the needs of people living with HIV/AIDS and promoting the active engagement and leadership of PLWHA established partnership with other parts in the world, specially in Africa and the Caribbean countries. There are many National networks of PLWHA in the world, for example, PLWA in Australia which advocates on

behalf of people living with HIV/AIDS. This umbrella works with government researchers and pharmaceutical services. (<http://www.napwa.org.au>)

In Africa, for instance, we can take the cases of South Africa and Uganda, whereby such national networks seem to be well established. The success of South African NAPWA movement had to do with the strong experience of *civil society*. This has been able to draw on the organizational and advocacy experience of the anti-apartheid movement as well as the gay and lesbian movement. It attracted educated individuals and professionals as well as poor and marginalized people (Centre for Policy Studies, 2001: 36).

NAPWA (National association of people with AIDS) in South Africa is a non-discriminatory organization, formed in 1994 seeking to promote a safe and secure involvement that guarantees the basic Human Rights and dignity for those who are HIV positive. This organization strives to provide care and support to the membership as well as to mobilize and organize lobby and advocacy. NAPWA is, moreover, an organization whose membership is open to all people living with HIV/AIDS. Its most important programs are: mobilization, advocacy and lobbying, partnership and collaboration, gender program, organizational development and counseling and support (www.napwa.org.za).

The same structure can be found in Uganda where, because of the seriousness of the situation there, civil society, together with government, labor and business had to be strongly involved in HIV/AIDS related matters. There is an umbrella of people living with HIV/AIDS called TASO, and the 'AIDS services organization'.

The impact of these organizations even though some important achievements is still relatively limited, considering the rapid spread of the disease; Goss and Adam-Smith (1995) argue, however, that pressure groups formed by PLWHA were being represented in organizations and trying to articulate an appropriate response.

One of the most important lessons Africa has learnt in the fight against HIV/AIDS pandemic is that of '*multisectoral approach*⁴', which has proved to be a condition for successful battle. It means that all stakeholders namely government, private sector, the civil society and the media at all levels '*must come together to find ways to work against the common foe*' (Thornton 2003: 23).

HIV/AIDS and Gender Issues

"HIV/AIDS has a female face"

Worldwide in 2004 there were about 37.2 millions adult people living with HIV, of them 17.6 were women and 2.2 children (UNAIDS: 2004).

In Africa the number of women infected with HIV outnumbers infected men. Twelve point two million African women are living with HIV/AIDS as compared with 10.1 million men young African women between 15-19 are four to six times more infected than young men of the same age (Tallis, 2000:26).

Rachel Royce in Vallaers, in her article about *Awareness Is Not Enough: Gender in the HIV/AIDS Pandemic in Africa*, gives considerable ideas on the impact of gender relation and HIV/AIDS. She remarks that HIV has been called a "biologically sexist" virus by scientists, because women are in much greater danger of contracting the disease during sexual intercourse than the man. In the absence of sexually transmitted infections, a man with HIV/AIDS has an average chance of one in 500 of passing the virus to a woman in a single act of unprotected vaginal intercourse. The odds of woman-to-man transmission in the same situation are about one in 1000.

Women under the age of twenty are more likely to contract HIV because an immature genital tract has fewer layers of mucous membrane, increasing the chances that the virus enters the bloodstream. In the presence of lesions in the genital tract, the risk of contracting HIV increases up to sevenfold (Rachel Royce :2005).

⁴ This is the Ugandan approach, developed in the early 1990s.

But Women are not only at a biological disadvantage, but at a social disadvantage as well. World Health Organization (WHO), "Fact Sheet No. 242," June 2000 mentioned that "the second-class status of women in economic, social and civic life has fuelled the pandemic in much of the world." In addition, as Lesley Doyal, a Health Studies expert of Africa, pointed out that "women cannot use condoms in the way most government programs recommend. Instead they must persuade men to do so, and this can be an extremely difficult task." She further argues that in traditional African relations, women are not expected to discuss or make decisions about sexuality. Women do not have control over condom use, they also have little control over their husband's sexual practices. Women are placed at a high risk of contracting the virus, not from their own behavior, but from the behavior of men over whom they have little control.

It looks like women are victims of a patriarchal system that robs them of the freedom over their own bodies.

It is once more clear how women are disadvantaged in protecting themselves.

Following Rachel Royce in Vallaey's (2005) in a culture that places such high value on family life, and in which family size is an issue of gaining status and respect in the community, it may very well be futile to urge married couples to use condoms. In this case, not using a condom is in the best interest of the woman as well, because "in many societies, motherhood represents the only route to status, identity and personhood, and ultimately security and support in old age. As one can see, conception cannot be combined with safe sex, and most Africans want large families. Not only is the joy of having children enough reason to disregard the advice of using a condom, but there are other cultural and economic factors as well.

Given that the configuration of gender relation in Africa is associated with sexual behavior and economic security, this relation not only underlies women's particular vulnerability but also inhibit women's security and their families (Beylies: 2000). It is also believed that it is "Only when gender inequality becomes a central part of HIV/AIDS programs can we then hope to make an impact on the course of the epidemic" (Tallis, 2000: 5) So, in addition to biological and social factors, the economic situation of women in Africa also contributes to their increased endangerment of contracting HIV.

The study of rural household in Uganda has revealed that more women are dead than men. The same author remarks, however, that in countries where the majority of infected people are men, women living with HIV/AIDS are often invisible. This means that their needs are not articulated or if they are, they are not heard and not addressed ((Tallis, V., 2000: 61).

In most African countries it is women and men in the midst of their productive and reproductive lives who are most likely to become infected by HIV and die. However, given a typical age difference between partners of five to ten years, females tend to be infected at younger age. Women are infected at an earlier age. Given more rapid disease progression with age, husbands often die more quickly, leaving more widows. (Baylies: 2000:10-12).

Mozambique would not be an exception this gender issue UNAIDS also confirm that the number of women living with HIV/AIDS is growing, and women experience socio economic inequalities and discrimination, particularly aggravated with the deterioration of socio economic conditions in the country given the adoption of market economy, the makes the life waste for women concerning to access health and social services.

www.info.usaid.gov/pop-health.

African men easily forget the fact that performing sexually with many partners place them at risk of HIV/AIDS infection. This in turn has impacts on women who have little power and control in sexual interactions. Such power dynamics in heterosexual relationships raise issues in relation to HIV/AIDS that have been addressed in other

contexts, for example – sexuality, relationships access to health care, women's burden/role in health care and reproductive rights. (Tallis, 2000:60).

This is an indication of how this work cannot achieve more without addressing the issue of gender roles. It is in this regard that the International Community of Women Living With HIV/AIDS (ICW) was created in 1992 at the international AIDS conference in Amsterdam. ICW was created with a purpose to share concerns about the lack of support and dearth of information available to HIV positive women worldwide of Women Living with HIV/AIDS (WLWA) through challenging discrimination and stigma with self empowerment and self-sufficiency, dissemination of information, skill-building training research and advocacy (Artman, 1989: 25).

To return to the importance of our research regarding HIV/AIDS, let us finally remark that in discussing the issue of HIV/AIDS, safe sex and risk reduction, there is a need to take into account the way in which high risk sexual behaviour is embedded in systems of socio-cultural, economic and political exchange, particularly those systems of exchange, which typify gendered power relations between men and women. But all in all, we are enriched through this literature review to understand that HIV/AIDS needs a multiple approach rather than just a single approach

CHAPTER 4 - GENERAL OVERVIEW OF THE THREE PROVINCES IN STUDY

Introduction

The specific nature of AIDS epidemic varies from place to place, depending on historical circumstance, cultural context and contemporary political economy (...) disease is a social event, which expresses the central realities of the society in which it occurs''.(Bujura & Baylie, 2000: 25)

In the absence of a straightforward medical cure, understanding of the spread of HIV/AIDS and advice about how to intervene to limit its spread, should be largely social scientific in nature. Therefore, Social Sciences should provide the main components of the relevant knowledge-base. The very considerable regional differences of social phenomena require a particular mobilization of social science knowledge about each particular society or regional grouping of like societies.

Following this assumption this section focuses on similarities and differences in the three provinces and explains the various factors that may be behind them, in order to trace specific characteristics in the context of HIV/AIDS and its associations. It is important to speak of some economic and social factors related to HIV before speaking about HIV itself in each province. It has been observed, for example, that a high risk of HIV among people, especially adolescent is concentrated among the most socio-economically disadvantaged. There is, for example, a relationship between poverty and HIV/AIDS which includes the spatial and socio-economic distribution of HIV infection in Mozambique. That is why we will discuss HIV in each province by including social factors such as:

- geographical location;

- population mobility; and
- relevant socio cultural aspects that may be behind the HIV community in each province.

These general considerations will be followed by the story of HIV/AIDS associations in each of province.

Talking about HIV/AIDS and its associations which Altman (1994) prefers to call the Community-based organizations (CBOs), it requires first the understanding of what the term ‘community’ is all about because community is at the center of every association.

According to Altman (1994) the term ‘community’ is usually applied to a group of people defined by certain boundaries, such as race, ethnicity, religion or profession. In other words, community is defined in geographical terms; indeed, many of the central works in ‘community studies assume a geographical base to ‘community’. Others have given it a spiritual meaning, as in M.Scott Peck’s assertion that this term should be restricted to a group of individuals who have learned how to communicate honestly with each other, whose relationships go deeper than their masks of composure, and who have developed some significant commitment to ‘rejoice together, mourn together’ and ‘to delight in each other, make others’ conditions our own’ (Altman, 1994:7-8).

In light of the above perception, the author also agree with Peck’s definition of community as a group of individuals who have learned how to communicate honestly with each other and whose relationships go deeper than their masks of composure, and who have developed some significant commitment to ‘rejoice together, mourn together’ and ‘to delight in each other, make others’ conditions our own’. The author also believe that what makes these associations succeed in Mozambique is the fact that people living the same geographical space have the same culture (or belief system) and history to which they add the same sorrow imposed on them by the pandemic. All these things combined can help them to support one another and help them chart the best way forward.

But the question which still persists is what does being a member of a HIV Community mean?

Without a doubt each of these activities represents an important element that makes PLWHAs comprehensive HIV communities. If we go from the predicament that the best thing among people is the one which is the most beneficial for mankind, and that good members of the community are the ones who are productive and dynamic or the ones who care for the welfare of the Community, it is easy to deduce that PLWHAs are part of the HIV community seem to be involved more than the extent to which they personally benefit from the HIV people. They contribute for the benefit of others not looking for a reward. The above arguments give to the word community a broader context which includes both those who live with the virus and the organizations looking after them.

Maputo province

Geographical situation

Mozambique is divided into three geographical regions: south, centre and north. Maputo and another two provinces (Gaza and Inhambane) constitute the south regions.

This province has as its board countries South Africa and Swaziland.

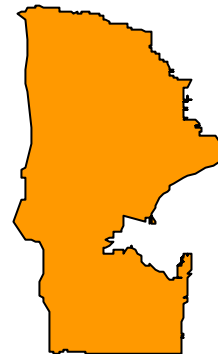


Fig.2 Map of Maputo Province

Population

In terms of population according to INE: 1997 there were 2.700 million inhabitants and the majority was concentrated in Maputo city, with about 1.800 million inhabitants. Maputo has a strong relationship with South Africa through mine labour migration since 19th century. Many people in Mozambique continue to cross the border legally or illegally looking for job in the mine areas or elsewhere like in the farms.

The International Organization of Migration (IOM, 2004) has shown that there is a straight relationship between HIV/AIDS and migration. The HIV infection is frequent in men who work far from home and live in single hostels like miners and others workers. For example there are many mine workers returning home when they are already sick-with AIDS. The risk of infecting others is in sexual relations with their partners while they are infected.

Beside all this, Maputo is part of an important corridor that links this city to Johannesburg, there are so many important roads that link this city to other country in the region such as Swaziland and South Africa from Durban. The same way that the mosquito transmits malaria and the dirty water cholera, HIV is transmitted by contact of people by travelling.

A quick look the city of Maputo clearly shows that in Maputo there is

- a confluence of people from different parts of others province who come to look for jobs or better conditions of lives;
- people from others countries embassies and international agencies are located there;
- there are the most important institutions such as universities, media, trade and enterprises;
- Important sectors of civil society are concentrated here;
- UN agencies and others international organizations, donors and most important meetings and debates about this issue are also held in this city;
- a variety of mass media that help to spread information in the different communities are also found in this city.

These aspects put Maputo in advantageous position over other provinces.

HIV/AIDS ASSOCIATIONS

By HIV/AIDS associations here the author mean the local Aids initiatives which are non-profit organizations dedicated to promoting HIV/AIDS awareness in Mozambique by scaling up nation-wide prevention efforts and improving the lives of persons infected with or affected by HIV/AIDS. Kindlimuka was founded by those who were receiving counselling from AMODEFA. Kindlimuka was created around 1997 in Maputo city. AMODEFA is behind the creation of this association and that is why the members of this association use to say that *AMODEFA* is 'our father'. The first years of its existence the association used the premises of AMODEFA. By that time AMODEFA was working on programs of family planning, giving counsel to couples about issues of reproductive health. The most important part of this association is formed by nurses and other health workers. After some time, it was able to detect people with HIV problems and started to give counselling in this matter also. In 2000 the number of associations increased in Maputo due to the increasing number of infected people who, in turn, contributed to the creation GATVs (Gabinete de Aconselhamento e Testagem Voluntaria) what means Services of Counseling and Voluntary Testing such as *Thinena* and *Kuyakana kudumba*.

In addition, there are many organizations working with people living with HIV/AIDS. Examples of these are *FDC*, *Muleide*, *Kulima*, *Forum Mulher*, *AMME* and many others. These organizations work with or for PLWHA in different parts of Maputo and other provinces providing specific programmes for the Mozambican community. FDC has a specific programme *Kulhuvuka* along Maputo corridor in south region working with widows and giving financial assistance and civic education to infected people while *Muleide Kulima* and *Forum Mulher AMODEFA* are working in partnership with the international institutions and health services in care based home assistance to PLWA..In very recent years *Vidas positivas* 'Positive lives' was created. This NGO's primary aim is to providing counselling to HIV positive people. This organization tries to implement some strategies developed in South Africa. *Soul City Agency* in South Africa supports its actions. *Soul City*, is a South Africa NGO that was established in 1992 to harness the power of mass media and promote health and development in South Africa

and beyond is actually achieving its dreams. Its TV programmes or movies about HIV/AIDS are now implemented in Mozambique to help people know how to handle HIV issues.

Unlike the other provinces, PLWHA associations in Maputo have the possibility to negotiate the implementation of different programs thanks to the direct intervention government departments and other facilities. In short, the dynamic of HIV people associations in Maputo are privileged because the central services of government are based in Maputo as well as the others international institutions including the donors.

Manica province

Geographical situation

Manica province is situated in the central region of Mozambique. This region is composed by three provinces (*Sofala, Tete and Zambezia*). Manica has Zimbabwe as its neighbour.

Population

The population in this province is about 1900.000 of which a major part is concentrated in Chimoio (INE: 1997).

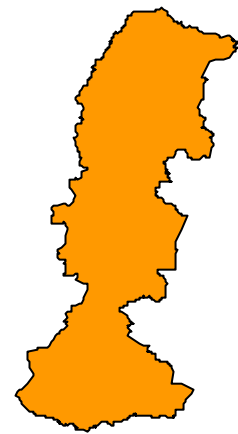


Fig.3 Map of Manica

This province was one of those most damaged by the civil war which lasted for some decades. During this war many people ran away from this province and went to other countries including Zimbabwe as refugees. During that time Zimbabwe was considered as one of the most affected countries by HIV/AIDS in Africa. It is often believed that the return of these immigrants (already infected by HIV in the neighbouring counties) to their own country after war also contributed to the increase or spread of HIV in the province or the country by large.

Besides this war, many socio-economic infrastructures in this country were also destroyed. The local government is still struggling to rebuild these infrastructures. Nevertheless, the recent political and economic crises in Zimbabwe have brought many

white framers from this country to Maputo and who have been exploring the land in this province. That is why Manica is seeing considerable improvement in terms of agriculture and trade these days. The infrastructures such as roads are also developing.

Similarly in Maputo there is in this region an important corridor created in 1990 as a way to strength the linkage between Mozambique and Zimbabwe. The corridor is from Port of Beira (Sofala) to Zimbabwe crossing Chimoio in Manica. This corridor brought large movements of people and goods from each country to another. This corridor, though economically important, has an impact on the dissemination of HIV/AIDS. The districts along this corridor (Beira, Dondo, Nhamatanda, Gondola, Chimoio, Sussundenga and Manica) are seriously affected by AIDS. The highest prevalence of HIV/AIDS in Mozambique is registered in this region with 26%, following by the south region with 19% and 9% in the north region (INE: 2004). The most apparent cause for highest level of HIV/AIDS prevalence in this province is justified by the immigration. Studies conducted by CEP⁵ also confirm that the internal mobility of people a long side this corridor has contributed seriously to the spread HIV/AIDS in Mozambique, in general, and in this region, in particular.

The HIV/AIDS Associations

Rudo kubatana is the first association that was created in this province since 1997. The province was the first one to become aware of the wide spread of this disease as it had noticed many people dying of AIDS by the end of 90s in Manica and more particularly in Chimoio. The return of displaced people from neighbouring countries was the most important reason. *Rudo Kubatana* in the first years of it existence was an important association aggregating many people with HIV/AIDS in Chimoio.

The thing that struck the most the author's mind here is the courage of people in this association in breaking silence about their HIV status (more details in chapter IV). At

⁵ CEP Centro the Estudos da Populacao (centre of population studies) belongs Eduardo Mondlane University

national level actions developed by this association became soon remarkable. Many of its activities gave this association the great reliability. Zimbabwean associations remained the role model of *Rudo Kubatana*. People learned quickly how to organise their association. They learned from what they saw happening in Zimbabwe as this country already had more experience in matters relating to HIV/AIDS as far as the 1980s.

Besides, Guinguirirai was founded in 2000 though its activities already existed since 1999. What is peculiar to Guinguirirai is the fact that emerged out of *Kubatsirane*, an ecumenical religious NGO. Among other activities *Kubatsirane* was working with PLWHA and in 2000 this organization decided to become autonomous. Thus it became autonomous even though it still remains part of *Kubatsirane*. It attends *Kubatsirane*'s meetings and gives advices on a number of issues. They still hold in common some concerns although they blocked out from each other. (Report given by Sister Rosa, coordinator of Guinguirirai, Chimoio: 2004)

GATVs in Manica started in 2001 as well as in many others provinces. In Maputo there is one support group as well as in Chimoio, Manica and Gondola districts. According to the provincial coordinator of Nucleo Provincial do Combate ao HIV/AIDS these three-support groups are preparing to form one association. The dynamic of the PLWHA in Manica complains about the financial resources to develop its activities as Manica people do not have many local donors to support their activities.

Zambezia province

Geographical situation

Zambezia province is part of the central region of the country. It has Quelimane as its capital city.

Population

Zambezia is the second biggest province and the second most populated with about three million of inhabitants (INE: 1997). Like

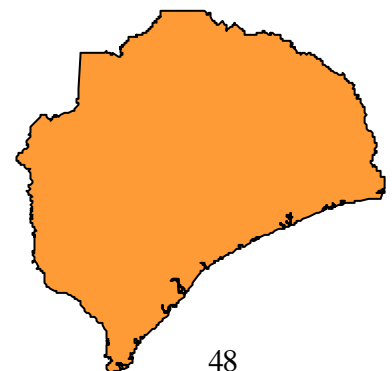


Fig. 4 Map of Zambezia

others capitals Quelimane also absorbs more than 1/3 of the provinces entire population that is estimated to be 1000 people (INE: 1997).

This province has Malawi as the country border. Like Manica province, Zambezia during the civil war saw many people migrating to Malawi as refugees. According to the data, the most refugee people of Mozambique during this war were based in Malawi (PNUD, 1996).

The linkage between Southern and Northern Mozambique is through the Zambezi River. To cross the country through this river is not easy due to the bad state that the bridges and roads in that part of the country. As result, many drivers prefer to make the turn around the river thus taking the route of north region via Malawi. Travelling by air is the fastest means of transport, but it is obvious that this is not given to the ordinary people without enough money. Despite the fact that the government is making efforts to rebuild the bridge, it is a fact that the Zambezia province remains is isolated from rest of the country. Maybe this isolation has for the time being preserved this province from high risk of conducting HIV/AIDS.

The HIV/AIDS associations

PLWHA associations in Zambezia like in Manica are not strong. PLWHA in Quelimane city has two branches: *Associacao Esperanca*, association Hope, and *Kewa*. *Associacao Esperanca* was created in 1997 and *kewa* in 2001. *Associacao Esperanca* has its origins in the provincial hospital. It is reported that this association started as result of blood tests. The increasing number of HIV people in Mozambique pushed the Blood services in this particular hospital to check all the donors of blood. Those found with HIV+ results were advised by nurses to share their burden together. From this mutual encouragement came the idea of starting an association. In 2000 other members of *Associacao Esperanca* decided to create a new branch, *Kewa*. This association is represented by a woman. *Kewa* is dynamic. It tries to extend its activities to other districts or provinces such as Mocuba, *Pebane* and *Maganja da Costa*. In terms of financial support, the PLWHA here get some support from the international NGO such as Action Aid, Save the Children and UNICEF.

“Empowerment” is the most important term to remember from PLWHA. It differs from traditional patriarchal benefactor strategies. PLWHA does not attempt to treat the HIV people as subjects; it emphasizes their participation and maintains the interaction between them, which we encourage here.

Conclusion

To conclude this chapter, the author first remarks that this study of social factors has reinforced our understanding of HIV/AIDS in these three provinces. We need, to remind ourselves that the organizations of PLWHAs need to shift their approach towards HIV. These organizations also have to approach the matter of this pandemic in different perspective. More efforts still need to be put in.

From this brief presentation of HIV overview of these three provinces, the author observed that there are several socio cultural factors that can influence drastically the dynamics of HIV/AIDS association. However two important aspects could be considered. For instance Maputo, the capital, presents more organizations working in HIV/AIDS, as well as, associations of people living with HIV/AIDS, while in Manica the active organizations could be explained by the fact of this province being close to Zimbabwe and learns from this country’s positive experience in this matter.

As a new phenomenon, HIV is a social event. At the same time, it demonstrates many unique features. This means that its impact on community life may be very different from one place to another. This section has shown that HIV/AIDS associations are capable of creating communities that not only facilitate connections between people but also provide supports for their members. Thus, the associations of PLWHA have not only the potential to promote and fight the disease among people in real life but also the capability to construct a virtual community that is part of the real life. The point is, the relationship among people with HIV through PLWHA associations becomes more and more significant. This means the possibility that PLWHA will eventually replace all other forms of associations not composed with people with the virus in the future is evident. This is proven by its new approach which is not only social-oriented but also problem-solving.

The associations of PLWA is formed essentially by poor people has led some to characterize it as a disease of poverty. However, evidence suggests that in some countries the wealthy are also especially susceptible to infection. But in general, it is likely that the poorest sectors of the population are still the most severely affected.

CHAPTER 5 - FINDINGS

This chapter begins with a brief description of the issue of stigma. It gives an overview of HIV/AIDS support groups and how these developed into associations. The comments offered by PLWHA in the support groups and associations are the most important part of this section. The chapter discusses, moreover, questions related to the internal organization of the associations. Also included is a discussion and interpretation of cultural issues obtained from the analysis of People living with this virus. The chapter concludes with a review of the funding in the fight against HIV/AIDS.

Stigma

AIDS-related stigma (or, more simply, *AIDS stigma*) refers to prejudice, discounting, discrediting, and discrimination directed at people perceived to have AIDS or HIV, and the individuals, groups, and communities with which they are associated.

AIDS stigma is expressed around the world in a variety of ways, including:

- ostracism, rejection, and avoidance of people with AIDS (PLWAs)
- discrimination against PLWAs
- compulsory HIV testing without prior consent or protection of confidentiality
- violence against persons who are perceived to have AIDS or to be infected with HIV
- quarantine of persons with HIV.

AIDS stigma is effectively universal, but its form varies from one country to another, and the specific groups targeted for AIDS stigma vary considerably.

Whatever its form, AIDS stigma inflicts suffering on people and interferes with attempts to fight the AIDS epidemic.

Here is a testimony of a man who was diagnosed as HIV positive in Chimoio, 2004:

I never told any body about my situation because I was afraid to be marginalized by them, even my wife I couldn't tell. I only spoke about my condition in the association because I knew that all were suffering from the same problem.

Another testimony quite different from the first one reads as follows:

When the doctor told me that the reason of my long disease was due to AIDS... I informed my husband. Since then, I was no longer at ease at in my house as result my husband decided to take me back to my parents where I am now. My sin was that I revealed the secret...
(Interview with a HIV/AIDS woman in Maputo, 2004).

As one can see, the issue of stigma appears in this second interview. Before, we comment more on the interviews; let us first understand what stigma is all about. Stigma is compounded by fear of an incurable disease, fear of death after long suffering, association of HIV/AIDS with sexuality, and a misunderstanding of its causes. Stigma is indeed deadly because it hinders both prevention of HIV/Aids and provision of quality care. It is also deadly because every human is a social being and when rejected, people become very affected causing death long before the virus could kill. Most of our African countries make the stigma a worse epidemic than AIDS itself (CEA/UEM: 2000).

It is now clear that those who accept their status could live for years, but those who cannot stand the stigma must die earlier than they should. This is very unfortunate because stigma is socially constructed, hence it is curable. An effective way of dealing with stigma is simply assuring people that they are better off knowing their status, that they need not give up if infected, and that there can be quality life after HIV. This is what PLWHA associations are trying to achieve.

These extracts of the interviews demonstrate the level of discriminations related to the HIV positive people, on the one hand, and the importance role played by PLWHA associations where people can talk to one another about their sero status and share experiences.

Origins and motivation for creation of HIV/AIDS groups & associations

The difference between support groups and associations is that the support group is an informal group while the association is a formal group recognized legally by the ministry of justice on one hand, and the existence of structure elected by the assembly on the other. But the objectives, characteristics of the members, the activities are the same.

Some times people of the certain support groups are also members of the associations. It is worth signalling here that most support groups are attached to the hospitals which are their spheres of operation.

The support group origins and function

The establishment of more GATV⁶'s services of HIV-AIDS voluntary counselling and testing help people to check their sero status. These services were created by the CNCS in coordination with the Ministry of Health. The aim of these services to ensure that any one who wants to know about his/her situation does it without any monetary costs. The services are intended to be countrywide provided in order to prevent the spread of HIV through sexual intercourse, maternal-child transmission as well as by blood transfusion. Given this context, the services attempt to reduce the morbidity of HIV- infection through early or prophylactic treatment of HIV infected individual what should include antiretroviral therapy.

According to CNCS, the above services will be provided step by step through the country. They are first guaranteed in the cities where people are the most concentrated. The same source contends that around 2010 these services will cover all health services (CNCS: 2004).

⁶ GATV Is an acronym meaning Gabinete de Aconselhamento e Testagem Voluntaria (Services of Counseling and Voluntary Testing)

Another important aspect related to these services is that wherever they are, they are backed up by **support groups** in order to give an emotional comfort to those people tested positively. As already explained, the integration of people in these support groups is done by GATV services. As soon as people have tested HIV/AIDS positive, they are immediately encouraged to become members of one of these support groups.

There are activists working in these groups whose job is to sensitize people to join the group.

One of the Maputo HIV positive activists went public on her own HIV status and had this to say:

I'm an HIV positive working in this GATV as an activist of this hospital. This job is important because people who receive positive results, if they don't get support of some sort they can even commit suicide. So we stand here as people went through the same experience but alive... and therefore can help others (Interview with an HIV positive activist, Maputo: 2004).

Ivone, coordinator of one of the support group also acknowledges the good results of her work:

I work here as a coordinator of this support group. I used to work for another organization sensitizing people door to door in the community. But when I realised that MSF Luxemburg wants some one for this kind of job, I applied and was accepted. I'm happy doing this because it is a great joy to see that the person who was knocked down by the disease stands up and walks after counselling. It is then that I realised that I am doing a useful job (Ivone, Maputo: 2004).

The drastic growing number of infection in the country and the presence of the support groups can help people to become more and more open and seek for hospitals where they can confirm their status.

It is in this context that Maputo support groups such as Thinhena, Kudunba, Kuyakane and Thinhena youth were found useful to HIV-people. In Manica province there are support groups in Chimoio 'hospital dia', in Manica and Gondola. In Zambezia - Quelimane there is also a support group operating in the 'hospital dia'. Considering the experiences of the already existing associations created from these support groups, it could be assumed that more HIV-associations will emerge in Mozambique. Some of these support groups have contracts with institutions such as Medicos Sem Fronteiras Luxemburg and Switzerland.

One thing that is clear is that none of these messages have led to behavior change. Many of those who were interviewed belong to these support groups and say that they feel secure and happy as members of these groups because they have the opportunity to talk, to share the same situation with others. A woman from Thenema support group confirmed this feeling saying:

When I knew that I'm HIV positive I thought I'm going to die...I really lost the interest in life... but now in this group, I learnt that I'm not alone and I can live longer if I take care of myself (Member of Thinhena, Maputo:2004).

These groups are important because, after a person receives a positive result of HIV feels emotionally down. As a young girl pointed out:

*When I knew about my results, I felt abandoned and already dead".
(Member of Kindlimuka, Maputo: 2004).*

To elucidate how these support groups operate the author single out *Thinhena*, the group that the author worked intensively with. The author attended many of its meetings and conducted interviews with many of its members. This group was formed in 2000 as a result of the establishment of GATV in health centre of *1 de Maio* in *Polana Canico*. The group is supported by *Medicos Sem Fronteira* Luxemburg.

In *Thinhena* there are more than 90 members that meet regularly weekly following the established calendar:

Monday is the day of general meeting (i.e. for all members of the associations) where they deal with general issues related to their status and the stigmatisation they are victim of in their work places and how to handle that.

Tuesday is the women-meeting day. On this day it is only women of the support group that are allowed to attend this meeting. Ivone Joaquim coordinator of this group says that she understood that women in the general meetings didn't speak comfortably about their problems. This attitude is caused by gender- power relationships already emphasised on. Women are afraid to expose their ideas and tell their experiences because they can suffer some reprisal from their husband at home.

Wednesday is the day of youth meetings. These meeting involve both boys and girls. Specific problems related to their age are discussed. The major concern of this group is to create awareness of how they have to deal with their future despite their status. Issues around marriage and education are also discussed.

On Friday pregnant women attend the (PTV⁷) *Programa de Transmissao Vertical* 'Vertical Transmission Program'. This program of prevent mother-to-child transmission of HIV is supported by USAID in conjunction with the Ministry of Health and others partners. This started in 2002 most in urban areas making a volunteer counselling and testing available for pregnant women as part of antenatal care including greater use of safe delivery services, family planning to reduce mother-to-child transmission, and anti retroviral therapy (Nevirapine) for these positive pregnant women (USAID country profile: HIV/AIDS). Beside all these aspects is also including counselling on appropriate infant feeding.

As women are taught not to breastfeed their little ones and knowing that the level of income for most families in Mozambique is a problem, it was found that such meetings

⁷ An acronym in Portuguese meaning Programa de transmissao vertical what means in English program of vertical transmission. This program is about pregnant women attending the treatment as a way to avoid the transmission of the HIV to the baby.

be done in conjunction with some NGOs such as Santo Egidio and World Food Program in Maputo and Quelimane that supply milk to these babies till six-eighteen months though these programs do not still solve this problem given the fact that babies need milk up to two years. The question is often what will come after six months?

Vigorous controversy exist about whether HIV infected women in developing countries should choose the formula of breastfeeding their infants or not. Breast milk, as we all know, especially in the first months, are vital for the survival of the child because it contains nutrients and antibodies which are needed for the development of the immune system of the baby but have inherent risk of transmitting HIV to the baby. Not breastfeeding babies eliminates HIV transmission but incurs risk of increased mortality whereas breastfeeding has multiple benefits but entails risk of HIV transmission it is estimated by UNICEF that million non –HIV related death per year can be prevented globally through breastfeeding (Coutsoudis, 2002:15).

The other problem is that when infected women are asked why they don't breast feed their babies they have difficulty to explain the reason. Confidentiality is also at risk. Pressure from family especially mothers - in -law force young women to breastfeed thus, increasing the risk to their children to be infected.

From the support groups to the associations

According to the interviews support groups decided to become associations because they felt the necessity to act outside of the hospital and be recognized as groups which have the capacity to talk about situations on behalf of people living with HIV. They started to be organized in way to act outside the hospital, integrating both infected and affected people suffering from the same problem. They were encouraged to establish their own associations.

Then some members start to follow the necessary path to create a formal group with their own vision and specifics aims. Are examples Thinhena and Kubumba in Maputo.

«..we thought to create our own association to explain our situation to whom it concern...and we wanted to be recognized as a organized group

of one's own free will to fight against HIV/AIDS breaking the silence(...) another problem is that the donor institutions only give support to organized groups and recognized by the government...». (Elias president of Thinena , Maputo:2004).

This is confirmed by Elias in Thinena association who says:

We thought to create our own association to explain our situation to whom it concern...and we wanted to be recognized as a organized group with our own free will to fight against HIV/AIDS, breaking the silence(...) Another problem is that the donors (institutions) supported only formal organized groups recognized by the government. (Late Elias president of Thinena association, Maputo: 2004).

Rensida, a national network of PLWHA has been useful by supporting some groups preparing their documentation to become associations. This national network has been supporting also in writing projects and finding donors to support these associations. The most important role of this national network is to co-ordinate the activities of its members, on one hand, and to represent interests of its members in the government and others institutions. It is in this spirit that associations such as Thinena and Kubumba in Maputo were formed.

Overview on the associations

In Mozambique two phases can be distinguished in the creation of HIV associations. However, our purpose is to highlight them and the different metamorphosis they took overtime. The first category could be sent back to 1997-9 when timidly people of HIV/AIDS formed the first associations. In this time these associations were hidden and only people directly related to them knew about their existence. Some NGOs and others institutions were behind the creation of them stimulating PLWHA associations to work with. Later on, these people decided to organize themselves into their own associations. Examples can be given of *Kindlimuka* in Maputo in 1996 and Kubatana in Chimoio in 1998. This word '*Kindlimuka*' means in Tsonga 'wake up'. In other words, it is an invitation to take action as time has gone.

This command fits very well in the context of HIV/AIDS matters where people need to wake up and fight against HIV. Kindlimuka, the first group of its kind in the country, was founded in 1996 and officially recognized in 1998. Today it has more than 330 members, of whom the great majority is HIV-positive. The association strives to reduce the stigmatization of people living with HIV/AIDS by breaking the silence and speaking openly of the illness. It encourages other groups of PLHWAs to seek official status for their associations with the aim of establishing at least one association for each province in the country.

Rudo Kubatana in Manica province is the other association belonging to this phase *Rudo Kubatana* in *Shona* language these words are expressed to encourage HIV positive people to stay together in love ‘people has to be together and in love with each other’⁸.

Associacao Esperanca in Quelimane-Zambezia also means in Portuguese language ‘Hope Association’. This is a challenge to HIV- positive people to think positively and be full of hope for future despite their condition.

The objective of these associations was to give the membership courage and hope. The native names given to theses associations attract local people who deeply understand the meaning behind these names. However, the idea that PLWHA associations can help HIV-positive people is not new, nor is it exclusively African. It does exist in other places as well but seems to be a successful approach in the Mozambican context. The success rests on the fact that most HIV-people feel free to share their burden with their peers who suffer from the same disease.

The second generation of associations of PLWA can be considerate since 2000 until nowadays, in this period observed a “boom” of these associations, the reasons behind this increasing of associations could be associated to the awareness of the government with

⁸ This explanation was given by the president of Kubatana association in Chimoio during the interview in 2004

this pandemic that culminated with the creation of the CNCS⁹ in 2000 a governmental institution with the task to coordinate all actions related to HIV/AIDS countrywide. This measurement shows that the government was committed now more seriously. The HIV/AIDS was assumed as an emergence national matter so including in the priorities of its agenda. (Plano Estrategico Nacional: 2004)

PLWHA as a tool to Breaking the Silence on HIV/AIDS Epidemic in Mozambique

As the fight against HIV/AIDS intensifies in Mozambique, more and more people living with the virus are volunteering to share experiences but we should admit that this is still happening in the confines of these associations or support groups mentioned above.

Janzen in the quest for therapy in lower Zaire found that the people with the same problems, are more confident and the communication becomes more simply when they share the same culture .(Janzen: 1978).

As long as people are ready to talk about it, HIV/AIDS has spread at a fast rate in this country. People living with HIV/AIDS in the associations share their experiences with one another. This indicates that people start now to accept the reality of HIV/AIDS and respond with full understanding of the complexity of the epidemic and the socio-economic challenges it is posing to the nation.

These associations are the best way to deal with HIV as many people make their HIV status known there. The associations also present talks to various groups, help organize HIV/AIDS awareness and education campaigns, and provide HIV/AIDS pre-test and post-test counseling and psychological support to those infected and affected. It is believed by many that people living with HIV/AIDS are potentially the most effective educators, counselors, campaigners and care givers given opportunity and support.

⁹ CNCS Conselho Nacional de Combate ao Sida is an acronym in Portuguese meaning: National Council of Fighting AIDS.

People living the virus are starting now to make HIV/AIDS visible through personal testimony, using sensitive training, prevention campaigns and workplace counseling to bring AIDS into the open and encourage an effective and humane response by governments and civil society.

But their meetings remain the first place where the silence is broken because they are open in speaking about their problems. Those who have lived with disease long enough share their experiences with the new members to encourage them. A senior woman of Thinhena support group declares this, for example:

Times ago people in my district used to point fingers to me saying that she has AIDS. I was ashamed about, but now when I hear some one point to me in that way I confirm my status and I advice him/her to go testing because he can be also in the same situation like me....(Amelia, Maputo:2004).

The whole idea is to give a human face and voice to the epidemic in the minds of people not directly touched by it, "We want to facilitate the acceptance of the presence of HIV/AIDS in the community" (Onen, 1999:2). The more we start talking about the epidemic, the more people will accept it as a reality and refrain from behavior that would put them at risk.

Those in positions of power should strengthen the capacity of communities to discuss the epidemic and the changes they must introduce to survive, and increase effectiveness of national HIV/AIDS policy development programs as the community-based organizations (PLWHA) have started to show the example with its counseling and care activities programs.

Intellectuals should also contribute their knowledge and experience to decision making processes to ensure effective national response to the epidemic. We need to know that we are all at equal risk contracting the virus. Above all the government must make information and tools for prevention and support available to all citizens, increase investment in programs for young people, promote the development and implementation

of policies and legislation that will ensure the epidemic attains priority in the government's budget.

Characteristics of the members the Association

I attempted to gather full data on the characteristics of these members including sex, age, level of education and employment. However, because of different reasons such as the lack of update data base of associations, it was not possible to find these aspects in all associations. Except in two associations *Kindlimuka* and *Associacao Esperanca*, it was possible. The presentation of this data is an attempt to give a picture of what these associations are like. This data is reliable because it is full of inconsistencies.

Characteristics of the associations

Organizations.	Location	T. number	male	female	employment	education
Kindlimuka	Maputo	330	124	206	85 ¹⁰	¹¹
Kubatana	Manica	138	66	72	65 ¹²	
Shinguirirai	Manica	100	40	60	25 ¹³	
Associacao E	Zambezia	350	150	200	22 ¹⁴	50% ¹⁵
S g. kudumba	Maputo	About 50 ¹⁶	32	18		
Thinhenha	Maputo	80	30	50	80% - 15% ¹⁷	

Table 2 characteristics of members of the associations

¹⁰ This number of people employed in this association seems to be high because it includes activists

¹¹ Information about education is not possible to be presented in the table because the data are estimated. For example, the number related to high education is referring to honorary members, while, 35% of the members in these associations never been in the school

¹² Most of them as activist employed through the association

¹³ All employed as activists

¹⁴ 17 of this number are working as activists 8 outside of the associations

¹⁵ 50% are illiterate while the other 50% attended primary school and a few % secondary school

¹⁶ Means that was not possible to get the precise information due to the fact that some member no more attend the meetings of the group

¹⁷ This association estimated the data in % where 80% are unemployed and only 15% employed

Associations must be managed and run primarily by People Living with HIV/AIDS, both affected and infected but mostly the infected ones. They must have or establish a board and officers, as well as an elected finance sub-committee, and a medical advisory team. They must also keep minutes of board meetings and up to date financial records. Associations must demonstrate that they do not discriminate on the basis of gender, religion, ethnicity, sexual preference, and social class; or against sex workers and drug users. The selected members should have demonstrated commitment to their own health by their past and present behavior, such as participation in the association's Positive Living programs.

In short these groups can be represented as this:

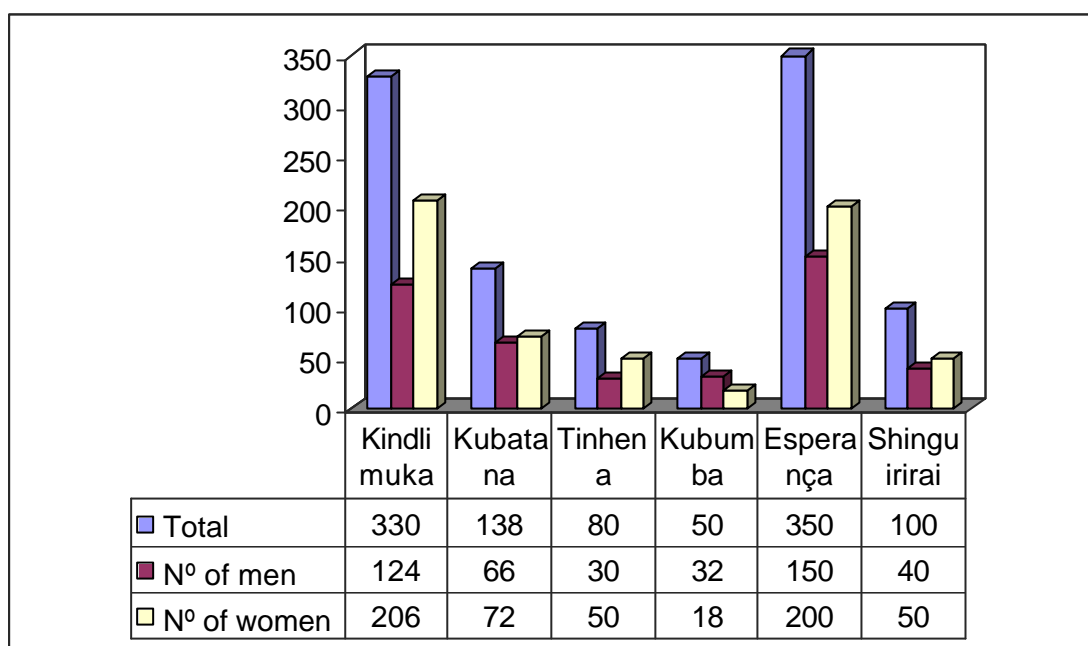


Figure 5. Distribution of Males and Females in the Associations

Gender Issues in the associations

Following the above tables, it is clear that the number of women in all associations is higher than that of men. This is because women find themselves in situations where they need to be tested than men do. They get tested when they are pregnant, they are advised to have an HIV-test and if they are found positive, they are integrated in the associations. Patton confirms this when she says that “many times these women are surprised confront with this situation in conjunction with undergoing some other forms of health care mostly related to their reproductive health” (Patton, 1994:128).

But beside these reasons the number of women increases in the associations because some of them are taken by their sero positive husband advised in the hospital to check their wives’ status. By contrast, women do not have enough power to bring their husbands to the associations. An HIV-positive woman confirmed that when she knew about her situation, the hospital advised her to take her husband for testing. The husband in return responded angrily saying:

get out from my home, I don't want to hear this in my place if you have got AIDS it is your problem don't include me in your affair

As already emphasised in chapter 2, the relationship between women and men in Africa are characterised by asymmetrical power relations, which constitute real barriers to women's social development. Women are always silenced by men in many aspects, especially when it comes to sexual matters.

In fact, if we accept that the most important means to transmit HIV/AIDS is by heterosexual where both men and women can be affected the gender relations are indispensable to be considered. In African society the "women often have too little power within their relationships to insist on condom use, and they have too little power outside of these relationships to abandon partnerships that put them at risk" (Baylies, 2000:6).

Even as Baylie and Bujra think that the best thing to do would be for women to challenge men's power and negotiate for safe sex (Baylies&Bujra, Xii: 2000). But this challenge is not an easy task considering the process of socialization in Africa including cultural practices such as polygamy and rites of passage (initiation rites) that put women more and more in subordination conditions. In these practices women are taught to surrender before the male power if they have to be good house wives.

In almost all African cultures, "women's worth is equated with their child bearing and proofs the men's masculinity (Patton, 1994:140).

To confirm and reinforce this argument it could be important to state the following quote from one of my interviewees:

I'm 29 old and have got three children. The oldest is of my first marriage. He is 14 and another is 9 and the last is this baby here. These two last are of my second marriage. My husband died five years ago. I was always sick and had a skin disease (herpes) and TB as was diagnosed at hospital. I was convinced that I will soon die because I had the same symptoms which my husband had.

Given the persistent of my illness I had to consult the doctor and he advised me to take a HIV test. I did and the results were positive. Finally I was told that I'm HIV positive. At the hospital I was advised by an activist of Kubatana to join his association. So, after the first visit, I decided to be a member of this association. The first day when I get there I recognized many people there because some of them used to come at my home with my late husband as his colleagues. So I realised that every day when he said that he is going to work, he was actually coming to the association. I remember that he never told me where he was working and what kind of job he was doing. My husband was HIV/AIDS positive and he knew it, but never told me about his status. The life at home was natural until he died. Now I have another partner and I got this baby but last year my baby died. We are together in this association....

When asked if she knows that it is not good to have babies because they can die as result of this sickness, she replied:

I know, at hospital they teach us about these things. They say that it is not good for an HIV positive to be pregnant because the body will get weaker and weaker and eventually die. But what will I do? I'm still young and my husband says that he can only pay lobola (bride price) at least if I have a child with him.

In my family no one knows about my situation. It is not easy to tell people about this disease here in Chimoio because you can be discriminated by all people including the family members. Now I'm working here at the association as a cleaner as a way to have some money to support my children.

We speak of African women as being sexually subordinated by men. That topic is also debatable because on the biological point of view, women still have an important role in African society. A proverb from Ghana declares that: A woman is a flower in a

garden; her husband is the fence around it.'" (1). That is a beautiful picture of women in African society. The main idea here is to link human life directly with God through the woman. She is created by God, and in turn becomes the instrument of human life. She rightly becomes the one who passes on life. With such a belief, African people both men and women see the bearing of a child is very important than the fear of having one's child infected by HIV/AIDS.

Level of education

The second aspect that comes out from these associations is the level of illiteracy. A country in which 70% of the population resides in poverty and illiteracy the disease (HIV/AIDS) can only be expected to be rampant. This is so because the community has no exposure to programs that can help them and inform them to fight this pandemic and therefore the risk of vulnerability of infection will continue unless alternative measures such as the ones by PLWHA are effectively adopted in the entire country.

There are many reasons for AIDS education. The first of which is to prevent new infections from taking place. People should be given information about HIV, how it can be transmitted, and how people to protect themselves from infection. A second reason that AIDS education is needed is to improve quality of life for HIV positive people HIV+ people should be taught about the importance of not passing on the virus. The third reason people need AIDS education is to reduce stigma and discrimination. In many countries there is a great deal of fear and stigmatization of people who are HIV positive.

This fear is too often accompanied by ignorance, resentment and ultimately, anger. Sometimes the results of prejudice and fear can be extreme, with HIV positive people being burned to death in India. Discrimination against positive people can help the AIDS epidemic to spread - if people are fearful of being tested for HIV, and then they are more likely to pass the infection to someone else without knowing (HIV&AIDS Education, 2005)

It is a fact that the people who are most urgently in need of HIV education and in these associations are poor or ordinary people. Those educated people who hold high positions in the government or local authorities though HIV+ are completely absent in these

associations. They get their assistance or treatment from private clinics or outside the country. This is so because of the fear of discrimination in Mozambique.

Unlike these educated people, the uneducated ones feel free to talk about their sero-status. They appear on TV programs confessing publicly being their sero status. TVM program “Vidas positivas” makes efforts to bring middle class people to do the same but they timidly respond to this program’s invitation. Maybe the reason why the poor people easily break the silence is because they have not much to lose and in so doing they know they will maybe get some money or others forms of compensation to face the starvation problem.

This was confirmed by two young boys in Chimoio who told that when they broke the silence by declaring their HIV status they used to receive some incentives.

“... when we gave this kind of information about our HIV status we used to ask for some incentive... and coming out in the open is not easy... many organizations used to give us some money...” young boy from Guinguirirai Association, Chimoio: 20004).

From a handful of courageous individuals who went public about their HIV status in 1999 in the capital, Maputo, there is now a nationwide network of 28 associations of people living with HIV and AIDS (PLWAs) (Rensida: 2004). Yet stigma and discrimination persist.

Considering the level of education and employment, one can conclude that these associations are weak. On one hand, it is not easy to do voluntary work and the same time try to feed the family since the majority are unemployed and on the other hand, because the members are illiterate, they can not make well-informed decisions in the running of the associations.

The general picture of Mozambique is that is a poor country ravaged by AIDS with a high employment and low education level. Despite this picture, there are some rich people in good positions in the government and civil society. Although these may suffer from AIDS, usually they do not belong any of these associations.

This kind of attitude is not good when you want to break the silence. Mozambique is still not doing well in breaking down the culture of silence among influential people. The experience of Uganda shows that when influential people come out in the open and announced their HIV/AIDS status, more people were influenced to do the same. It also led to an increase in sensitization of the general public on issues that relate to HIV/AIDS.

Organizations like TASO and individuals like Pilly Lutaya in Uganda “ put a human face to HIV/AIDS” . Ordinary people were able to associate AIDS with rich people, and joined hands together in fight against HIV/AIDS. (<http://www.aidsuganda.org/pdf/role-ofvct.pdf>).

Unlike Mozambique in many countries such as South Africa we hear stories from people who live or have in some way been affected by HIV/AIDS. They reveal their status honorably. However, for the vast majority of people living in these counties, human rights are respected and people have learned to live with HIV+ people with dignity. This is a good example to follow for Mozambique where everyone needs to learn how and why not to discriminate against positive people.

Altman comparison of HIV organizations in Africa with those in USA found that in the USA these organizations are far stronger and organized in terms of political representation and advocacy than they are in Africa or other developing countries (Altman: 1994: 58-59). In our understanding what makes them this way can be attributed to wealth, fight against discrimination and high level of education of those working in these organizations.

Employment and HIV care

HIV-People in Mozambique, estimated at 13% of the total population within a country continue to face difficult lives without access to any basic services.

Education, Transport, Health and Employment services do not exist or are very scarce and do not satisfy the needs of this social group. The mass media do not give attention to the specific needs of people.

Mozambican society in general, continues to look at people with disability including HIV- people as useless and incapable; subjects them to constant marginalization and discrimination; and gives them no space to participate in the massive effort of recovery and development of the country.

It is important to observe (see tables 1-7) that most members of the associations are unemployed. In this item we used two categories of employed people: one referring the people employed outside the association in public, private or informal sector, and the other referring to people considered employed by the associations working as activists in the GATVs or hospitals. Since they receive their minimal incentive, they consider themselves as employed people.

This incentive correspond about 500000\$00mts equivalents about R 150\$00 per month. This amount is insignificant if it has to cover the needs of a household with at least 5 to 6 people. In INE and PNUD report, Mozambique is considered as one of the poorest countries in the world where people are living with less than one UDS dollar per day. The actual minimum salary in Mozambique is 1.200.000mts meanwhile the basic needed for a household of 5 people are calculated in double of minimum salary in 3.300.000mts (OTM Cental Sindicato: 2003)

Given the low possibilities of employment most people in these associations are concerned in having this kind of job as an activist and they consider themselves as employed despite this low income.

For example in Maputo the coordinator of the Kudumba support group, said that when the association was formed most of members got employed as cleaners or gardeners at the hospital where the association is based. That attracted other people to join the group so that they could benefit from the incentives. It, was not possible to employ all or the people because the jobs were limited (coordinator of Kudumba, Maputo: 2004).

It is in this regard that the board of the association came to the understanding of the fact that people working in the association with children to look after qualify (should obtain)

for such support grant for survival. The president of association Kewa in Quelimane argues:

One of the most important objective of the association is to ensure that the members have the minimal for survive... many of us are not working because we lost the job due to the illness... so we have to do something for them in that way (Ana of kewa association, Quelimane:2004).

In this way, we see the PLWHA as having gone one step further from their emphasis on HIV/AIDS education to care. Education was (is) important, but now that the pandemic is full-blown, the need for care had become more urgent.

In South Africa a disability grant of R740 per month (US \$108) is available to people with CD4 cell counts below 200. It is believed that HIV-people who cannot work find themselves in the category of those with disability and are eligible to such grant.

Unfortunately, there are some misconceptions among the young girls who sleep around with men without condom. They do not mind contracting HIV so that she could access the disability grant. Here also the South African government (the department of social development) has the duty determine how to improve the grant system and prevent such perverse incentives.

Caregivers need to receive a salary, which can help them and their families to survive. We do, however, agree with the fact these people have been trained in basic nursing skills, but are not health educators or full nurses as such. But it is also true that they cannot work for nothing.

In short, a number of issues impinge on the PLWHA's contribution to HIV/AIDS. High illiteracy rates, unemployment, underemployment, lack of scientific awareness of HIV/AIDS epidemic, a high population growth rate and cultural misconceptions, are some of such issues affecting the policy that PLWHA proposes to address.

Description of the association's offices

This section describes PLWHA addressing HIV/AIDS in Mozambique that were visited during my research in Maputo and other provinces. The offices outlook, the associations' functions and chart will be presented as well.

To start with, most of the offices of the associations are small houses in annex of the main house (dependencia) and in degradation situation (i.e. without renewal painting, electricity and water) with the exception of kindlimuka in Maputo and kubatana in Chimoio whose offices are independent properties.



Figure 6 This is the office of *Kindlimuka* association with the logotype in the main entrance

But both of them faced some problems related to the payment of the rents. Kindlimuka , for example, moved twice from one office to another in 2004. Kubatana was in search of a less expensive and affordable office as their donor notified them that he will stop paying the rent simply because the association mission in the province was nearly to finish.

Others associations work together with NGOs or other institutions as they are unable to afford the rent. This is the case of Guinguirirai in Chimoio working at Kubatsirane office. Kuyakana in Maputo is also working in the premises of the Rensida office while

Associacao Esperanca is with MONASO in Quelimane. And finally Kewa in Quelimane is given a small room in the provincial hospital.

It is also important to emphasise on the fact that these offices are located in hidden places. Is not easy to find them unless one is taken by hand to these places as they do not even have the advertise signals pointing to where they are located.



Figure 7 the road to get the *Thinhena* association some where in the district of Laulane close to Maputo city



Figure 8 The *Thinhena*'s office association

Mozambique faces many challenges. Even though PLWHA continues to play a paramount role in educating people about HIV/AIDS and sharing of experiences with the government, the political parties about this pandemic.

Structure and function of these associations

The way in which HIV people associations are structured is based on the one adopted by the most of NGOs in Mozambique. To be legally recognized an association in Mozambique an organization has to be recognized by the ministry of justice. Ten members at least have to sign the status in representation of the others members. Others requirements are: the *estatutos*, describing the aims of the associations, general presentation about the members, the structure of function of the different organs.

The basic organization chart looks like this:

The structure of the organisation: Principal organs and the function

Organization Chart

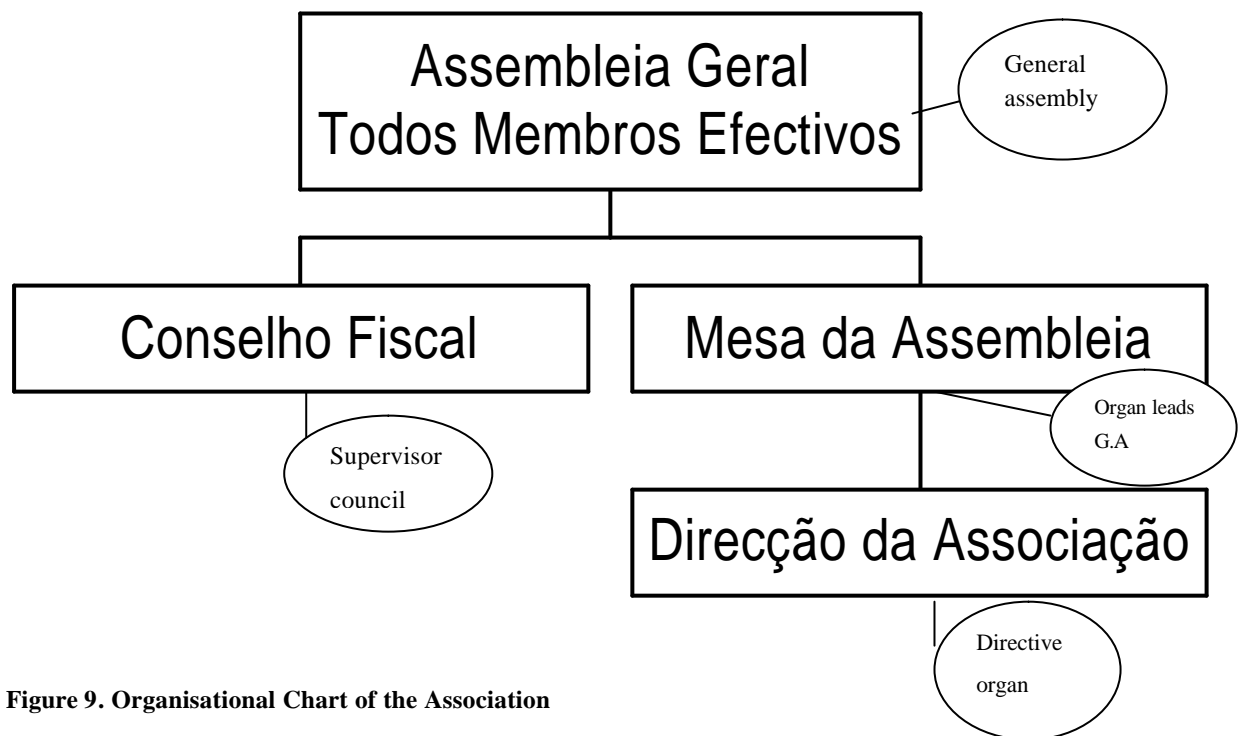


Figure 9. Organisational Chart of the Association

Sources: This organization chat was based on different status of the association (Thinhená, kindlimuka, Muleide, AMMe, kubatana).

Function of the associations

According to this chart the principal organ is the **General Assembly**, a president supported by one vice president and one secretary composes the presidium of this assembly. This is the main organ because it is where all aspects regarding the life of the association are being discussed. The alterations of the status, admission of new members, examination and approval of annual activities reports as well as financial reports are also part of this organ's agenda. The ordinary meetings occur once a year while the extraordinary can occur anytime when required by the direction or by 1/3 of its members.

Below the general assembly comes a **Directive Organ**. This one is composed by a president, one or two vice presidents and the executive secretary. This organ is the executive structure that deals with the daily activities of the association. The directive organ represents also the interests of the members. It is, in addition, responsible of the mission and vision of the association in the country and outside.

The **Executive Secretary** is not elected in the general assembly; he/she has to apply for this position according to the requirements set up by the association. The secretary spends her/his days coordinating meetings, making travel arrangements, and managing schedules. In between, she answers telephones, emails, and faxes. His/her major function of the Executive Secretary is the coordination of activities from the association's members, donors, and the international organizations.

The other important organ is the **Supervisor Council**. It is also composed by three members who are: the president of the council and two vocals members. This is also an important organ because it supervises all the activities of the association.

Normally these organs have the duration of three/ four years. Candidates of different organs have to observe three conditions: (a) to be effective members, (b) to be a HIV+ and (c) have leadership qualities.

As far as the schedule of other organs is concerned, their members have specific meetings weekly. They also have sometimes meetings with the directive members to analyse different activities.

As regards **the membership** of the association, we distinguish three general types, which are:

- The effective members,
- The honorable members and
- Sympathetic members.

The effective members are all HIV+ people who identify agree with the aims and objectives of the association. They are the key members not only in terms of numbers but mostly because they are the real cause of the existence of the association. Most of them are recruited through the activists working at the GATVs services. These activists start by presenting their associations and explaining the advantages of being member based on their own experience. It is in this way that they have been able to convince and attract as many people as possible. The process of becoming a member usually follows the same pattern. One member explains this process as follows:

[...] In 1999 continuously suffered from malaria and headache. I was also losing weight considerably. The medicine I was taking didn't solve the problem, so the doctor advised me to take a HIV test... the result was positive. Before the test I was asked by an activist of Kindlimuka to be a member of this association, and I joined.

Another member in Manica explained how he became a member of Guiguirirai in this way:

I took an HIV/AIDS test because I was always sick. I was told by some activist of this association about the advantages of being in this association. So I decided to visit the association and later I became a member...

Most people become members of the association after being referred to them by activists in the hospitals and GATVs. Stories such as these are numerous. Two aspects came out: the first one is that people normally go for a HIV/AIDS test when they got a persistent disease. The other aspect is that people become members of the associations because of the job of the activists at the hospitals inviting HIV positive people to join these associations.



Figure 10. Members of Kindlimuka association in the office.

Honorable members are people with influential positions in the society. These are, for instance, the members of the government or the civil society. In the Kindlimuka association we have members such as the prime minister, the minister of health of Mozambique, and the national head of HIV programs in the health ministry. There are also members of international agencies who contribute financially for the advancement of the association.

We have finally the **sympathetic members**. This category includes people working in the field of HIV from different sectors of the society as well as people working in the health services. It also includes anyone interested in HIV matters.

Rights and obligations of members

To be involved in the activities of the association gives one the freedom of speech in issues related to the association. Any member is in the obligation of paying a symbolic amount of 1000.00mts (i.e. some cents if converted in South African rands) as a symbolic contribution to the association.

Being a member of an association is very beneficial. One of most important benefits could be to access automatically the ARV treatment but is not what is happening. The government has a policy on the provision of antiretroviral treatment (TARV) that

involves these associations. The section of the Anti-Retroviral Treatment in Mozambique (Section 4.4.3.1) below expands more on the benefits of being member of the association and the role of this treatment.

The association and the Anti-Retroviral Treatment

As part of their rights members of these associations stand the chance of benefiting an efficient HIV treatment.

In theory, there are 3 strategies to contain the HIV/AIDS epidemic:

- To vaccinate everyone against HIV;
- To change sexual behavior;
- To provide anti-retroviral therapy (Gorik Ooms, 2004).

Of these three, the two first will take time before the change occurs. The countries, who favored the prevention via change of sexual behavior such as Uganda, now start to upscale anti-retroviral treatment. Effective anti-retroviral treatment seems to be the best option today but it requires patients to know their HIV positive status in an early stage of the syndrome.

Kindlimuka and GASD were among those associations that tried to address this issue of anti retroviral treatment in their programs. But according to the rules of the country the anti retroviral treatment (TARV¹⁸) is administered following the principles below:

To be eligible for this treatment one must fulfil the following:

- The confirmation of HIV/AIDS positive test by any national service of health.
- The level of CD4¹⁹ cells must be tested below 200 (point which indicates AIDS).

¹⁸ TARV is an acronym in Portuguese meaning Tratamento Ante Retroviral translated to English could be Anti Retroviral Treatment .

- Have at least one individual around who can assist in administering this treatment.

It should be noted, however, that this treatment is provided to all those who are infected by HIV independently if is or not a member of any association. This program is in the responsibility of the Ministry of Health. The ministry has a national program for this kind of treatment. There exists a specific program that is at the disposal of the members of HIV /AIDS people that belong to the associations. In other words, this treatment does not privilege any one but every body has right to it.

According to this ministry the TARV already started in Mozambique in 2000. Each hospital receives for the TARV program at least 75 new cases per month. In all provinces the workers of this program confirmed that people are really adhering. In Chimoio, for instance, the Dia hospital receives more than 75 new cases per month because this Hospital has been receiving also patients from different districts of this province. (Interview with the director of health, Chimoio: 2004).

According to some patients the effects of this treatment are visible and the treatment is therefore seen as effective. One of the patients at Maio Hospital acknowledges:

[...] when I started this treatment, I was too slim I couldn't even work, my mum had to carry me like a baby...but now, as you can see, I'm now putting on some weights ... people don't believe that I am sick (A patient of I de Maio hospital and member of support group, Maputo:2004).

However, to be administrated such a treatment, it is important to be aware of its side effects. Therefore one needs to feed on a solid and nutritious diet. But as many people live under poverty in this country, we believe that starvation could be also the major reason for deaths. On the other hand, interrupting such a treatment does not help the patient at all, it does, instead, create the virus' resistance to the medication.

¹⁹ CD4 or (t cell) lymphocytes are a group of white blood cell that normally help guard the body against attacks by bacteria, virus and other germs. When CD4 has decrease progressively to 200 cells or below the person has developed AIDS (<http://www.intelihealth.com/IH/ihlih/ws/h www/>)

Anyway, Muleide, an activist working in some suburban area in Maputo one said that people in general are reacting well to the TARV programs. Another aspect to it is that, the experience of care home-based care services are applied in so many developing countries because the health services cannot afford to deliver their services to a huge number of infected people. As a new experience there are some difficulties in dealing with them. That is why it is accepted that HIV associations deal also with such cases though requiring a little bit of expertise that most activists do not have.

The important is that the ART is shown efficient to minimize the AIDS. People who already started this treatment have given good reports. The Mozambican government is lobbies also to have more money in order to subsidize these drugs for more HIV positive people. The actual cost of ART treatment in Mozambique is about \$ USD 250 year per person. Is too expensive for a poor country like Mozambique, that's why the CNCS National council of fighting HIV/AIDS assumes that the first strategy should be the prevention. (Plano Estrategico Nacional: 2004).

Activities & responses of members belonging to the associations

Much of the counseling, education and peer education work which is carried out with HIV positive people is conducted by HIV positive people. Many projects are shaped by HIV positive people themselves, given the insight they have into what it is like to live with HIV / AIDS. A good example of such a service - run by HIV positive people for HIV positive people - is *Kewa Association* in *Quelimane* where one of the members stresses the unity among members in the following terms:

*Here we are like brothers and sisters. We use to come here to talk each other because at home we don't have the same comfort we have here
(Member of Kewa association, Quelimane: 2004).*

The other membership expressed also his feeling in these terms:

I can't lie to you. I'm feeling much better here than at my own home. Here I got friends with whom I can joke and talk bout any thing... So, I come

every day here and spend my day joyfully (Kewa association, Quelimane: 2004).

In short, these associations in all the three provinces are developing the same activities:

- Mutual support in the association through home visits.
- Educating people at the market places, in schools, workplace by making use of themselves as examples of HIV positive people.
- Giving counselling at the services such as GATV and hospitals.

The activists of these associations receive themselves a special training from national organizations such as AMODEFA and MONASO working in conjunction with the ministry of health. The activist's visits not only are important for the patients suffering with AIDS but also by enriching contact with the family members and advice about the illness. In so doing they help those who are not sick to know how to support the family members who are infected by AIDS. They become aware of how the disease is being transmitted and reduce the fear they might have by increase their compassion and cooperation for the patients.

It is worth repeating that civic education plays an important role in sensitising people about HIV/AIDS, especially when it's being conducted by an HIV/AIDS infected person. The message has greater impact on the audience because the messengers talk about their own experiences as people who live with the disease.

The home-based care and treatment is very important in many respects. Firstly, it enlightens the family members who are ignorant about how HIV transmitted. Secondly it helps in teaching family members to be compassion to HIV/AIDS patient because the activities are compassionate. It can be agued that the home based care treatment in Mozambique is supplemented by grassroots organizations. So, it is believed that this treatment can become more and more effective and sustainable if grassroots organizations are linked to existing public health services. However, this linkage is not effective because the public health care services are inadequate and insufficient.

The other activity undertaken by these associations in order to sustain them is income generating activities. These include the following:

- Embroidering and weaving different materials for sale
- Selling traditional medicine which is extracted from African potato
- Subsistence agricultural activities

In brief, this grassroots' action and other activities have an impact on PLWHAs by providing secondary income to sustain them.



Figure 11. These members of Kindlimuka Associations sewing staff of selling



Figure 12. *Some member of Thinhena association making vases for selling also*



Figure 13. This picture also is showing a group of women swing

Family: An important source of support for HIV-positive People

People diagnosed with HIV often turn to friends for support, and that's encouraged by doctors and therapists. But Ohio State University research suggests this advice may not go far enough. In Serovich's most recent study, published in the journal *AIDS CARE*, she found that the 134 HIV-positive men were less likely to be depressed if they received support from their families. In another study of 142 HIV-positive men, published in *AIDS Education and Prevention*, she found that subjects who received social support from their families were less likely to engage in risky sexual behaviors than were men who did not get social support from their families.

Serovich does not say that all HIV-positive people should tell family members, nor does she believe all family will be supportive. Some may, in fact, be hateful. So, HIV-positive men should consider seeking guidance from therapists or other helping professionals in making decisions about disclosure to family. And therapists need to encourage exploring those options.

People often need help in figuring out how to disclose their HIV-positive status to anyone, and it's important that they do so. It has been observed that people who disclose their status are more likely to get necessary medical help and find out about clinical trials, new therapies, family support or other options available to them than those who do not disclose their status.

In most cases HIV family members in Mozambique have problems supporting their family members who are sick. This is partly due to lack of knowledge of how to deal with the sick, on the one hand, and to lack of disclosure of those who are sick to their family members, on the other. In fact, many of these HIV positive people argue that it is difficult to inform the family members about their status as well as involving them in the association except in cases where the husband was tested positively and the GATV advises him to bring the partner and this one is also tested positive. But generally speaking families are not involved as pointed out by a member of Esperanca association who once said that

My family doesn't know that I belong to this association. In fact, I never told them ...not even my wife. Because I don't know how they will react (A member of Esperanca association in Quelimane: 2004).

In Chimoio a member corroborates this idea when she says that

I didn't know anything about this disease until my husband who was always sick and had skin problems for years asked me to go with him to the hospital one day. There I was tested HIV positive. He finally revealed to me that he was he also HIV+. This is how we are together in this association (An HIV positive woman in Chimoio: 2004).

This shows how women rarely learn about their husbands' status.

In cases where the woman goes first to the hospital and asks her husband to attend the consultation at hospital this one often responds in these words

You, go if you think you are sick, I'm fine (A member of Thinena support group, Maputo: 2004)

It is clear that the power of the man surpasses that of the woman in Mozambican patriarchal society as such man has a power to influence his wife to go to the hospital and not vice versa.

The anti-retroviral treatment referred to in section (4.4.3.1) requires that family gives support to HIV patients. In fact, when people start the TARV treatment the health service worker obliged them to tell members of their families because of this treatment once started it cannot be interrupted, and these drugs can bring out collaterals symptoms that it becomes therefore important that the family member encourages the patient to go further with it. The counsellors in Maputo association are aware of that as one of them remarks

When people have to start the TARV treatment we require that they come with at least one family member to will be looking after the patient at home. This person needs to be informed about the TARV treatment and its

effects in order to assist the patient whenever he needs help (Officer of MSF, Maputo: 2004).

It is wrong to assume that family support is mostly needed when the patient goes through the anti-retroviral treatment. This support is needed even for orphans (victims left behind by HIV/AIDS deceased parents).

Support for orphans by family network

While we praise Mozambique for its initiative to create its first hospital for HIV-positive children officially opened in Maputo on 24 May 2004 as the country was struggling to cope with more than 30,000 children born each year with the virus that leads to AIDS, we encourage the country to make however a further step. In fact, one of the most devastating aspects of the HIV/AIDS epidemic today is also the growing proportion of children the disease has orphaned. Unlike most diseases, HIV/AIDS generally kills not just one, but both parents. What is more, the stigmatisation and discrimination that people affected with HIV often live with is passed onto their children, making their fight for survival much more precarious.

When parents or caregivers fall sick and die, a child's life often falls apart. With HIV and AIDS, the hardship hits well before children are orphaned. First a parent or caregiver becomes ill with HIV or AIDS, and is unable to work. The entire family feels the economic impact – children, especially girls, must often drop out of school to go to work, care for their parents, look after their siblings and put food on the table. The situation becomes worse, as already said, when both parents die.

If there is one dimension that PLWHA needs to look at very attentively is to develop a system where children can be protected in their environment by the extended families. We believe that African traditional solidarity is naturally a framework that can be exploited and encouraged by governments to take care of children who had lost their caregivers. In this regards, UNICEF believes that whenever possible, children who are orphaned should remain in their communities to be raised by their extended family. Recognizing that family care is far better for children and far less costly than institutionalized care, children who grow up in families also develop better social skills

and are psychologically better adjusted than those who grow up in institutions because they receive more affection and attention and develop a better sense of personal identity (www.unicef.org/aids/index_orphans.html). We totally agree with such an approach, which we believe should be given thought in Mozambique as well by PLWHA.

PLWHA Organizations and fund opportunities

PLWHA & Other Organisations

As already mentioned in chapter 1, the National Response to HIV/AIDS in Mozambique is positive. It passed through several stages. The National Control Programme against STD/AIDS (NACP) was created in 1988, and the first Medium Term Plan (MPT1) was developed. The NACP has a central body, located in the Ministry of Health, and regional offices in 11 provinces. The main responsibilities of the NACP include planning, coordinating, monitoring, and assessing provincial plans, and providing technical assistance to government sectors involved in the program. The NACP also develops short- and medium-term plans and establishes cooperation protocols for Mozambican and international NGOs, donors, and social, religious, and mass media associations. A second Medium Term Plan (MPTII) was developed in 1994. The National Strategy to combat STI/AIDS includes prevention, counselling, epidemiological surveillance, and blood testing. Specific components of the national program include management, information, education and communication (IEC), epidemiological surveillance, laboratory support, care of PLWHAs and counselling, and condom social marketing (Plano Estrategico Nacional).

Organizations in Mozambique such as (MONASO) brought together a variety of organizations working on HIV/AIDS activities throughout the country. MONASO's credit is to have prepared an organizational strategic plan to provide more effective coordination and assistance to local NGOs. With increased disclosure of HIV-positive status, a network of PLWHA has also been formed, and partnerships have been created between the network, other NGOs, and the government

Donors/Funding

Though PLWHA organizations are involved in counseling and psychosocial support, home-based care, training of members, education and awareness activities, these organizations still face various management problems including inadequate technical skills to run their organizations and difficulties in raising funds.

PLWHA in Mozambique have had access to financial supports over years that strengthen and support an expanded response aimed at preventing transmission of HIV, providing care and support, reducing the vulnerability of individuals and communities to HIV/AIDS. But most of the members of PLWHA associations when interviewed refer to finances as the major problem that causes troubles within the associations themselves and their relationships with other institutions. If we consider Elias argument when he says that

We got good relationships with the foreign NGOs; they give us money to develop our activities. The problem is that we don't get that money on time even after the contracts are signed. (Elias at Thinena association, Maputo: 2004).

Such a quote shows that not only these PLWHA associations had nowhere to turn to for assistance, but the PLWHA organizations are faced with organizational problems as well because many members do not have the necessary skills to run the organizations. They need to develop advocacy, fundraising and communication strategies to overcome these problems.

But before we go into all that, let us first remark that multilateral and bilateral donors are actively engaged in Mozambique. **UNAIDS** has a coordinating theme group based in Mozambique since the 1990s. The group, chaired by WHO, consists of representatives from UNDP, UNFPA, UNESCO, The World Bank, WHO, and UNICEF. In addition, major bilateral donors who provide the bulk of AIDS financing in Mozambique are active leaders of the group.

The World Bank supports HIV prevention as part of a road construction project. WHO is carrying out joint activities in the areas of epidemiological surveillance, STI and HIV/AIDS counselling, prevention interventions for vulnerable groups, and blood safety. WHO also provides some direct support to NGOs. UNDP is implementing a comprehensive national AIDS project. UNFPA will support improved integration of STI and HIV/AIDS services into existing reproductive health services in its country program from 1998 to the year 2000. Finland's Ministry for Foreign Affairs, Department of International Development Cooperation, supported a \$1.1 million community development project from 1995 to 1997. The project, implemented by The Red Cross of Mozambique, provided information about HIV/AIDS, nutrition, maternal health care, and hygiene, as well as blood transfusion services.

Pepfar (President's Emergency Plan for AIDS Relief), Mozambican government is now one of the recipients of US President George W Bush's \$15bn Emergency Plan for Aids Relief (Pepfar). But the beneficiaries of Pepfar cash are only allowed to buy drugs approved by the US Food and Drug Administration (FDA). This effectively rules out the vastly cheaper generic treatments that Ms Muhai benefited from. Orla Ryan (2004), BBC News business reporter in Mozambique says that Pepfar represents a healthy injection of cash into the fight against HIV/Aids. Just as importantly, it is the result of US recognition that action is urgently needed.

Private Voluntary Organizations (PVOs) and Nongovernmental Organizations (NGOs)

A number of PVOs implement activities in Mozambique, funded by multilateral and bilateral donors. Some of the major USAID cooperating agencies include The Futures Group, and Population Services International. According to UNAIDS, a relatively small number of NGOs are working on HIV/AIDS prevention and they are concentrated primarily in Maputo and other urban areas. The majority of NGOs receive their funding from external sources and work at a micro level, with limited impact on the epidemic at the national level.

These NGOs, however, do not assist financially unless the associations fulfill certain requirements. This is maybe what the adviser of Rensida (National Network of PLWHA associations) meant when he said that foreign NGOs and donor institutions are tough when it comes to financial support. They give money only when the project submitted to them fits their requirements. Sometimes this is not easy as the organisations have to adjust the project in such a way that it suits them in order to get money. So this kind of relationship is that of dependence. The organisation totally depends on those who have money to function.

This shows that the associations do not have a good dialogue with donors. The organisations have at all cost to accept their conditions simply because they have resources which we do not have. This situation has turned many people to deal with HIV issues depending on how able they are to plan or write a project and not out of real passion for HIV people. People in desperate need of income would go for project NGOs require in order to get finances (Motlhaolwa: 2001: 27-28).

Caution should be taken, however, not to generalize this situation because our research reveals that some international donor agencies are flexible and are willing to discuss and altering the implementation of projects presented by PLWA associations even if it does not fit their agendas.

Accountability is another problem that arises when dealing with financial support issues. In fact, most of these international NGOs demand the associations to give account of how the money given has been used. MONASO and RENSIDA are aware of this problem. Most PLWHA associations struggle with that problem. But it should be admitted that with good managerial skills, integrity, honesty and transparency this is not a big issue. There should be no fear of being accountable to somebody.

On the other hand members of the board of these associations manifest their disappointment in that even though they are given some money by their donors this money does not respond to the needs of the associations with its multitude of activities.

In response to this international NGO's and others institutions argue saying that PLWHA associations are not able to deal with big amounts of money due to the weakness that their administration presents. An officer points out

If they even have problem in justifying that small amount how can we trust them giving more money? (Officer of Action aid, Quelimane: 2004).

The officers are also reluctant as they believe that pumping in a lot of money for HIV/AIDS will not help as the money would be used for other purposes other than fighting against the pandemic. This is confirmed by Ivone who argues:

I don't think that all this money in Mozambique in name of HIV/AIDS is effectively used for the suffering people... there are so many organizations working in on this issue but why is it that the number of infected people increases daily? (Ivone , Maputo:2004).

In Chimoio a NPCS officer adds also that

Something has to be done in order to know really if what all these organizations say is true ... I started to organize the map with all details of each national and international organizations to find out what, where and how they operate in the field (Officer of NPCS, Chimoio: 2004).

As for the president of Thinena association in Maputo

The number of seminars and workshops run in this country and in the world if enough and if the money spent on HIV/AIDS was spent to a productive goal by then this disease could have been already minimized... (President of Thinena association, Maputo: 2004).

For him but the results in the fight against HIV in Mozambique are not satisfactory. According to the Strategic National plan with its new executive secretary it is important that the plan be shifted into another direction. He thinks that in the next few years to pay more attention to the suffering people mainly the orphans. It is in this regard that the CNSC has given more assistance to the orphan programs in the country nowadays.

Still on the front of funds for HIV/AIDS, others complain that they do not benefit from the few that come in for HIV/AIDS programs. The president of Thinena association in Maputo sadly remarks that

There is money for HIV/AIDS program in this country but we continue to die and suffer without food and unable to support our families... where does this money go? (President of Thinena association, Maputo: 2004).

This issue is very complex indeed. But despite all these disagreement between international NGOs and PLWHA associations and the members among themselves as regards funds, the activities of PLWHA cannot be undermined.

This section has shown how the epidemic has now advanced significantly in Mozambique, fuelled by labour migration, rapid urbanisation, high levels of poverty, insufficient health infrastructures and significant rates of sexually transmitted infections.

The Government of Mozambique has taken a robust stance, matched by significant international efforts to combat the epidemic. None of these have so far incorporated large-scale treatment programmes for people living with HIV/AIDS. The emphasis has been on prevention, awareness-raising, voluntary counselling and testing and palliative care.

The author looked at different institutions involved in this fight against the pandemic among which we have MONASO which is the AIDS-NGO umbrella organization funded in 1991. MONASO support the NACP in co-ordinating NGOs and CBOs working on HIV/AIDS activities. Nowadays hundreds of members are working under the guidance and support of MONASO in care and support, training of activists and peer-educators, PLWA, community mobilization, condom promotion and distribution. In each province there is a nucleus of MONASO. The most important activities carried out are: CBOs/NGOs mobilization – co-ordination and support, training for staff members, project design, Media and Government sensibilization and resource mobilization. An international NGO, PSI, is providing also technical assistance to the NACP through the implementation of a Condom Social Marketing (CSM) component.

Some private companies are participating with NGOs to facilitate IEC activities at the work place and are selling the NACP branded condom, JeitO. Around 1000 private sector commercial distributors of JeitO are currently throughout Mozambique. The World Bank & MONASO are in negotiation with many private companies for the obligatory inclusion of STD/AIDS prevention activities for the benefit of the project- workers (and communities surrounded) in the Roads and Coastal Shipping (ROCS) Project. In 1997, the UN Theme Group on HIV/AIDS has invited the chief editors of all major newspapers, radio and TV to discuss the possible roles of media in an effective AIDS program.

The Alliance has been working in Mozambique since 2001 and established a country office in 2003. It offers programmatic and organisational support to local non-governmental and community-based organisations, faith-based organisations, organisations of people living with HIV/AIDS and governmental institutions in the central provinces to respond effectively to HIV/AIDS. It enables orphans, vulnerable children and people living with HIV/AIDS to access quality care and support services through partner programmes in central Mozambique.

Mozambique is battling to contain HIV/AIDS and the government faces hard choices about funds that block access to the cheapest drugs. The Mozambican government is now one of the recipients of US President George W Bush's \$15bn Emergency Plan for AIDS. The fight against this pandemic still continues.

Having thus laid bare all these issues related to HIV in Mozambique, we now feel that the ground has been cleared enough for us to speak of the relevance of PLWHAs in Mozambique based on some history cases.

Relevance of PLWHA in Mozambique discussion

Relevance of the findings

This section is a summary of findings from the review of the author's experience on the work place and interviews with PLWHAs staff and members. Where appropriate, quotes from interviews and documents are included.

The author present first the findings related to the selected History cases's relevance, followed by PLWHAs intervention, their success and effectiveness. The report concludes with a summary of the lessons learned and considerations for the development of these associations up to 2005.

Before examining these history cases, it is important to signal that there are two views regarding the relevance of PLWHA associations: The first view is that these associations are very important because it is only through them that one is able to identify and bring HIV positive people together and assist them. Most HIV/AIDS positive people and national NGOs argue that when HIV people form (recognised) PLWHA associations, this prevents opportunists from getting money in the name people suffering from HIV/AIDS.

The second view, however, is that it does not matter whether there is an association or not because the members that are in the associations are less than the total number of people living with HIV in the country. In other words, not more than 1% of people with HIV/AIDS in the country are in these associations (INE, 2003). Therefore, people would like to see new ways of reaching HIV/AIDS infected people.

In Chimoio, a GTZ²⁰ official argues that:

'It is not important to have PLWHA associations in the country because of the financial costs which include both activities like capacity building and payments of staff members'.

She continues and argues that:

People in the board are the only ones who benefit in these associations and that many women do not see the benefits of being member of the association as they don't have key or high positions in these associations.

²⁰ GTZ it is a German Non Governmental Organization supported by the German government

Surprisingly enough the study shows the existence of GATVs in the cities even though more associations are being formed and expanding through the districts. Moreover, the testimonies of people living with the virus show clearly that these PLWHAs are of great impact in the lives of many Mozambicans if not all.

Presentation of some selected case histories

The focus here is on understanding the appropriateness and clarity of the goals and actions of PLWHAs in order to inform people about their effectiveness. The author analyzed these cases with the following questions in mind:

- Were the PLWHAs appropriate in terms of the needs and the expectations of the HIV/AIDS patients?
- Have they succeeded (at least morally) in assisting their patients?
- Were the planned goals, targets and outcomes clearly linked and comprehensive to people?

The following are some selected case stories of some HIV positive people in the associations. These stories can help us to better understand the problems faced by these people. This is to support the argument that people discover that they are HIV positive when they go to the hospital for other medical examination. Some extracts also elucidate the role played by the family in supporting their dear sick parent. Unfortunately there are examples that confirm that some times they hide their sero positive status prejudicing their partners. All in all situations, PLWHA associations helped these people in various ways to live with this disease without stress.

Case history 1²¹

Elisa aged 31, was divorced 6 years ago and is mother of two children. The oldest is 16 years, the second born is 13 years. The woman is educated up to grade 7. This woman was found at a support group called Tinhena at 1 de Maio hospital in Maputo. She told us her story:

I discovered that I was HIV/AIDS positive because from 2000, I was falling ill frequently. In 2002, I was diagnosed with Tuberculosis and the doctor advised me to undergo an HIV test because he suspected I was HIV positive. I went through the test and the results were HIV positive. I didn't believe the result and as soon as I started to feel better I dropped the treatment. A few months later, I got sick again. So I decided to resume treatment because I thought that I would die if I didn't take the treatment seriously. Now I'm feeling much better.

After getting divorced from her husband she started to work for a private newspaper as a cleaner to enable her support her children. When she fell ill she began to face problems with her employers. Her story continues:

[...] my doctor gave me a recommendation letter addressed to my office saying that I should avoid doing heavy jobs because of my illness. After presenting the letter, I lost my job, because my employers did not have light jobs for me and I was not given any terminal benefits. I took the matter to the Human Rights League of Mozambique. The case is still pending and I do not have any response yet.

I became sick two years after being divorced. I can say nothing about him. No one of my family knows about my situation. I'm afraid to tell them

²¹ For reasons of confidentiality, we will use pseudonyms (not real names) to refer to the people who gave us their testimonies.

because few months ago I lost my sister by the same disease, so I don't want to cause problems to my parents.

I live with my parents and my children. Before I lost my job, I used to help my parents with supporting the family from the little I had as a cleaner. They didn't know that I'm a HIV positive and when I fell sick I told them that I had tuberculosis.

I knew about the existence of this association for people living with HIV/AIDS group through that my late sister. I used to accompany her to this hospital and to this support group. In this support group we are all friends and we are treated in the same way

Case history 2

Jannet gives her own testimony in these terms:

I became sexually active when I was 15 year old. While I was a student I got pregnant and my partner organized the lobola.

When I got sick I was still living with my family and my husband. They took me to a traditional healer who told us that my illness was related to the payment of lobola. But since I didn't get better my husband's family took me back to my parents. Since that time, I never went back to my husband's place because he went to South Africa. But I knew that he was already sick before he left for South Africa. I am convinced having been contaminated by him. He was a polygamist with three wives including myself and had also many girlfriends.

None of us disclosed his/her HIV status to his/her partner, but I think that he started to undergo treatment and use to tell me that we will die together even if we separate from each other.

A few months ago I decided to tell my children that I am HIV positive. This was a way of warning them about the dangers of HIV/AIDS and preparing them to face the challenges of life when I will no more be there. I hope they got my message.

It is difficult for my father to look after us properly. At least he provides food and shelter. But I have to find ways to provide other things such as school fees for my children. I am now working as an activist for this support group. I hope we will have some incentive with time. Till now, we still struggle to find a financial support for our activities.

Case history 3

My name is Elisabeth aged 34 and mother of two children. The oldest is 16 and the youngest 14. I was married till my world was messed up in 98 when my husband died. When we got married, we were young and belonged to the same Christian church. We stayed together for 9 years and it was after that when my husband fell ill. I and his family thought it was a normal disease but he lost a lot of weight. When we took him to Machava hospital, he was found with tuberculosis and was admitted [Machava is a TB specialised hospital in Maputo]. When he felt better, he was discharged from the hospital and came back home. He discontinued his treatment and started drinking heavily. A few months later, he died. After my husband's death I also fell sick and was told at the hospital that I am HIV positive. Then I realised that my husband died from AIDS as well. Two years later, I had a boyfriend who was working in South Africa. I fell pregnant during the time I was there for visit. I thought of my HIV status and I realised that I had to make abortion. I asked my brother to assist me but he denied my request due to his religious belief. As a result my pregnancy grew up until I gave birth to premature twins but who eventually died.

Although I was ill during my pregnancy, my situation, however, became worse after I gave birth. I fell seriously ill, I had TB and herpes zoster. I went back to the hospital but the nurse was disappointed. She sadly remarked that I was not supposed to be pregnant knowing that I'm HIV positive. I apologised for my gaffe.

It was at the hospital where I found friends who introduced me to Tinhena association. I am now feeling better and taking the medication consistently. I love to be here because of the warmth atmosphere of friendship between us. I come here everyday. It is here where I find friends with whom we talk about our lives openly and support each other. We are comforted by the idea we have the same problem.

I am now living with the father of my late twins who also was tested HIV positive. I explained my status to him and he accepted to take an HIV test. We are living together without any problems. When I started the anti - retroviral treatment the nurse asked me to come with a family member. I took my father. (This is a condition for starting this kind of treatment in all hospitals). My husband's father helps us to support the family because both of us are not working.

Some of my family members know my HIV status but I have never told others about it.

While this story seems to have a happy ending, not all of them do.

Case history 4

My name is Jorge. I am 34 years age and have never been married but I used to have a lot of girlfriends. I stay with my brother, my sister-in-law and my nephews. My brother is the only one who is working. It was in 2000 that I started feeling that I was sick. While ago in South Africa I used to work as a security guard in a company in Gemirsten and had that privilege of going to the hospital for treatment. Despite these good efforts, instead of improving my condition was worsening. This is how I ended up loosing my job and was given money, just enough, to travel back home. In Maputo my family took me to traditional healer in Gaza province but there is no improvement.

The first and serious disease I suffered from in my life was a sexually transmitted disease. The hospitals in South Africa failed to solve

this illness. When my brother took me to the hospital I already had a lot of complications. Besides, I developed herpes zoster and lost a lot of weight. I was unable to move by my self.

I was asked by a medical doctor to undergo an HIV test and the result was positive. I was admitted and transferred to hospital “1 de Maio”. Before I started with my treatment, I was already left with 34kgs only. What a loss! I was put on an anti retroviral treatment which I have continued to take till now. Nevertheless, I regained weight and weight 68kgs now. I know for sure that HIV/AIDS is real. I have this disease because of having many girlfriends, many sexual partners. I was never concerned about safe sex. I trusted all of them, I never used condoms. See what happened now!

I was invited by the coordinator of the support group to attend the meeting after consultation with the doctor, and I joined this group. I learned quickly that that I was not the only person on earth with this problem. This is how I started attending meetings every week. Now I also invite other people to join our group.

No one in my family knows that I am HIV positive apart from my brother who took me to the hospital, therefore, I have never been discriminated against by any of my family members or neighbour what ever.

As activists we have a project to visit fellow HIV positive people at home, we are not receiving any incentive but we hope that we will start receiving that very soon. If we had some incentive, that would be good for us, we would be able to look after our families and continue to work without worries.

Discussion of Findings (case histories)

These examples of case histories are what one should consider as revealing the reality of HIV/AIDS in Mozambique. These examples also may put to rest any argument that PLWHAs are not doing a proper job in Mozambique. They prove beyond any doubt that

PLWAs associations give real support to HIV positive people in this country. These case histories, moreover, represent and continue to represent several cases of HIV peoples bad and good experiences all over the country.

In the first interview (and many others that come after) Elisa shows how she only went for an HIV test when she realised that she was seriously sick. Like her in Mozambique most people realise that they are HIV/AIDS positive only when they frequently fall ill and are advised to take an HIV test. Based on our interviews 100% of people in the associations knew about their situation because of the persistent illness. The author is, therefore, tempted to generalise that people in this country never decide to have HIV test before they can experience illness. Yet having HIV test before one is seriously sick can increase chances for one to protect himself. Researchers suggest that the proper strategy for battling AIDS is to attack the virus. Most researchers, however, believe that the best approach is to treat HIV early, since this may preserve the body's own defenses against HIV.

Reading Jannet's story in interview 2 makes the author at first glance to think of polygamy as one of the main causes of HIV infection in Mozambique. In Mozambique, HIV infection increases because husbands who usually have a number of sexual partners. It is often to hear of stories like this by Stephanie Nolen (2005) about Azarias Mateusse and his four wives. *It has been four years since they buried Azarias Mateusse in the crowded cemetery in Xai Xai, but his shadow still looms large over the little concrete house where he lived with his wives. His first wife, Anita Manhiça, 43, is rail-thin and racked by a bone-shaking cough. These days she lies on a straw mat in the dusty yard, with barely the strength to tug a faded cotton sheet around her shoulders. She shivers, although it is 30 C. Azarias's second wife, Alba Houhou, 31, is starting to feel unwell. Some days she hardly has the energy to get dressed. She sends the children to fetch water from the village standpipe. And his third wife, Gracinda Invane, 33, has read the signs at Azarias's house; she has taken her two children and moved into town. But Gracinda, too, most likely has AIDS.*

Jannett is one of those victims in a polygamous marriage, whose marriage makes her end up HIV positive. Polygamy is the most frequent and main mode of transmission of HIV. Most HIV positive persons in this country have up to four partners (if not wives).

Another issue is that Jannett has been able to reveal her HIV status to her kids. In fact, deciding who to share your status with not only is a very personal decision but also a very difficult one to take. It may be hard to know if telling certain people will bring good or bad consequences. You might fear negative responses like rejection, discrimination, abandonment, or isolation. You might worry about being judged or feel guilty about past drug use or sexual behavior. In some situations, revealing your status could put you at risk for physical harm. Since some people may not be as accepting of your HIV status, these are all valid issues to think about.

Telling kids about one's status is not a practice which is common in Mozambique where it can be associated with taboo. If you have kids, telling them about your HIV status can be even more challenging. It is like telling them about other touchy topics -- such as body parts, puberty, and sex issues. But telling them can sometimes be rewarding.

Because on the Children with infected parents are a growing group who have concerns of their own: "Who will take care of me if my parents get sick? What happens to me if they die?" So, it might help them to start imagining their own destiny in this world without parents. But this depends on age since the youngest ones (0 to 10 year old) have nothing to do for themselves.

The National Women's Health Information Center (2005) writing about *Women and HIV/AIDS* acknowledges that there are mixed opinions on how mothers should handle this difficult decision. It provides however the results of some studies which show that open communication about the illness to their kids is better than not telling them. Children may already know something is wrong; keeping the illness a secret can confuse children and make them feel anxious. Other studies, the center argues, have found that children have negative reactions to being told, like behavior problems, sexual risk-taking behavior, and lower school performance. Several studies have shown that if a HIV+

mother reveals her status, telling a child to keep her health condition a secret is stressful for that child and as a result, that child may have behavior problems.

In one study, women with HIV who told their children about their illness were interviewed. They recommended these tips for talking to your kids about your HIV status.

- Think about why you want to tell your children. Make sure you're ready.
- Educate yourself about HIV so you can talk to your children about the illness.
- Plan for what you're going to say.
- Consider how healthy you are. It might be better to talk to your child when you're feeling healthy and can show your child a healthy, positive attitude.
- Think about other things going on in the family. It may not be the best time to tell your child when there are other stresses in the family.
- After you tell your children, get them additional support. They could talk to a health professional who can talk more with your children about HIV.

With regards to the above, we see that it took to Jannett a lot of courage to reveal her status to her kids. It is left to the reader to see where, when, how, why, and whether or not do the same once found in the same circumstances.

The author is provided with other encouraging issues by *Elisabeth Ricardo* in interview 3 whereby the speaker who supposedly contaminated her husband with the virus encourages him to confirm it with a test and the later surrenders. The author is also encouraged by the example given by both families supporting them even as *Elisabeth* started her antiretroviral treatment.

Unlike most cases where they have portrayed women as sexual objects by African men, here *Elisabeth's* example forces us to believe that African men are not all unreasonable. An HIV positive man can also make his partner understand that although she might be

the cause of his misery but he does not blame her for his own mistake for having not undergone with her for test before marriage. This makes the author also to believe that all the myths, stereotypes around African men being abusive can be challenged though still happening here and there. Gender equality has been firmly on the transformation agenda in Africa. Values such as respect of women's dignity and opinions are now recognized and getting ground.

Family support as, already discussed, is very important for HIV positive persons. *Elisabeth* example is of many which show that African people are good in providing practical and emotional support to their family members in pain no matter how the disease was contracted. (e.g. individuals living with HIV or AIDS). What they need maybe is a frame where a range of special services or training to those affected by their loved ones having HIV or AIDS so that they can now what exactly to do when the subjects undergo treatment, how to handle them.

In Interview 4 *Jorge* goes for traditional leaders to cure HIV/AIDS. It was also observed that some of the respondents consulted traditional healers at the same time that they are undergoing treatment in their respective hospitals. It is still believed by some people in Africa that HIV is caused by witchcraft or sorcery therefore *Sangomas* (traditional healers) or traditional healers are the only ones who can handle or solve such problems. This is easily rejected by science which believes that HIV disease has nothing to do with spirits intervention and therefore see it as a merely body disease. Whether this African belief is based on metaphysical dimension is a result of their ignorance or not, it remains, however, true that some people confess openly that traditional treatment is worth it.

AIDS action (2004) argues that 'western' or 'modern' medicine can reduce levels of HIV in the body and treat HIV-related opportunistic infections, but many people with HIV have no access to even the most basic western medicines. It is estimated that in many developing countries, particularly in rural areas, four out of every five people visit traditional health practitioners and use traditional treatments.

Traditional healers already treat large numbers of people living with HIV and AIDS. It is important to look at approaches to working with traditional health practitioners that can

improve HIV prevention and care services, while continuing to advocate for improved access to western medicines and treatment.

Some programs have trained traditional health practitioners in HIV/AIDS and other sexually transmitted infections (STIs). Appropriate training encourages traditional health practitioners to replace harmful practices or myths about HIV with safer practices. It can also help them to diagnose HIV and other STIs and encourage increased collaboration with biomedical or 'western' health services. This collaboration can have a number of advantages and biomedical health practitioners also need education in the benefits of working with recognized traditional health practitioners. For example, traditional health practitioners often have an approach to healing that takes into account the whole person - their mental, emotional, spiritual and physical health. Initial research into a variety of traditional treatments also suggests that some of these treatments offer potential relief from HIV-related infections; although like western medicine, none of these treatments is a cure for HIV.

This issue proper referring of *AIDS Action* looks at some successful approaches to working with traditional health practitioners and using traditional health practices to improve HIV prevention and care.

The traditional healers should be perceived as educators. This is so because respected traditional health practitioners see many clients and they can be very powerful educators. They have influence in the community, as well as with other healers through their professional networks. They understand local belief systems and can explain illness and misfortune in ways that people understand. It is important that they have correct information about HIV/AIDS and other sexually transmitted infections.

This paper argues that many people with HIV approach traditional healers even when they have access to other health services. One reason is that traditional healers usually treat the 'whole' person, not just the disease. They take into account a person's mental, emotional and spiritual as well as physical well-being. This can include contacting the spirits for help.

Traditional health practitioners often see their patients together with other family members and can play an important role in family counseling and in reducing stigma and discrimination against people with HIV/AIDS.

A quick look at these stories also revealed that what most of them share in common is that they often fail to disclose their HIV status (except to one case story). Most of the people interviewed confirmed that they did not tell any one of their family members that they were HIV positive until they started taking ARVs. This problem is related to discrimination and stigma. Similarly all complain about poverty and being unable to look after their family.

Finally, they all acknowledge the help they got from the support group or PLWHA associations. This frame provides a contact point and meeting place where HIV people get together and talk through their thoughts, fears, worries and frustrations without being faced with the stigma associated with the illness.

In short, people living with HIV/AIDS (PLWAs) can live positively with HIV longer if they talk openly about their problems and share information with others. Keeping HIV a secret could make those who are infected feel unhappy and stressed. Such emotional stress weakens the immune system. Disclosing (sharing) one's HIV status with someone else can help people get counseling, and help them get connected with others who are HIV-positive and able to provide support. In addition to people with HIV attempting to talk more freely, the entire community and religious leaders can contribute to the fight against HIV/AIDS by avoiding stigmatizing those with HIV and cooperating with each other to address the problem.

Conclusion

In this chapter the author has shown how HIV organizations have developed from support groups into associations. This was out of the need of becoming formally structured, be legally recognised by the ministry of justice and also to reach more people. It was believed that only associations could achieve these goals. The feelings, sentiments and desires of HIV people or PLWHAs members, their struggles and happiness in life both as individuals and members of PLWHAs were clearly expressed and presented in

this chapter. Most importantly, among their problems lays their need of being accepted in the society. The social responses of fear, denial, stigma and discrimination which have accompanied the epidemic for a while need to be dealt with. HIV people should not be denied access to the services and treatment they need. In Mozambique where HIV and AIDS are believed to bring shame upon the family or community, we insisted that good policy or law should help combat HIV/AIDS related discrimination.

Gender inequality was raised as one of the main cultural issues related to HIV in African and particularly in Mozambique. In this chapter, the have provided an overview of the gender-based abuses in this country that fuel the HIV/AIDS epidemic and make the lives of women and girls already living with HIV/AIDS unbearable. The argument was based largely on the horrifying stories told by women and girls who have suffered abuse from their husbands and in-laws. Through stories and voices of the women and girls and through research, the report illustrates the inter-linkages between human rights violations of women and girls and the HIV/AIDS crisis. It is hoped that an understanding of the human reality of these abuses will lead to greater protection of the rights of the girls and women at the center of a deadly epidemic.

The also spoke about fund raising. PLWHAs struggle to have funds though some efforts made by donors such as World Bank and others to support them. In fact, the author recommend that those HIV organizations (PLWHAs) that are serious about fund raising must also be committed to developing a rapport and reaching out to potential donors. Building relationships with donors, potential donors, local community and local government are essential. The more these organizations are kept informed, the higher the chances are that they will continue their support. The author also suggested that honest communication between the organizations and the donor can improve the lives of the sick people.

The author ended this chapter with case histories where analysis was made on some testimonies of HIV +people. It has been observed that people living with HIV/AIDS (PLWAs) can live positively with HIV longer if they talk openly about their problems

and share information with others. Keeping HIV a secret could make those who are infected feel unhappy and stressed.

CHAPTER 6 - CONCLUSION

Recapitulation of key issues

HIV/AIDS is a new holocaust that reaches all people independently of race, religious, sex, age or social position. The consequences of HIV/AIDS can be far-reaching for young people. Not only does HIV disease have terrible consequences for the individual, causing serious illness and eventual death, it has the potential to trigger negative social reactions. Across the world, people with HIV/AIDS routinely experience discrimination, stigmatization and ostracization.

The intrinsic problems posed by this pandemic constitute a new challenge. The increasing number of people infected by HIV/AIDS in the world has forced the infected people to be organized in groups or associations in order to face together the challenges of living with HIV/AIDS in the society.

The associations of PLWA and its members face many problems such as discrimination and stigma that is attached to the scourge. But notwithstanding these problems, these associations are showing an incredible dedication to addressing the issue of HIV/AIDS.

In Mozambique, the associations have specific and unique problems that are linked to the realities of the continent. These problems include poverty, illiteracy, cultural stereotype and many more. Despite the fact that many associations, in Mozambique as in other parts of Africa, are experiencing difficulties; some associations have done very well in their work. For example, the South African and Ugandan associations have so far demonstrated that they are capable of defending the interests of their members. For Mozambique, however, there seem to be no definite improvement to HIV/AIDS issues in Mozambique despite the good work which is undergoing there under the PLWHAs. The legal future of this population is unpredictable, it is less certain, but the author believes that, at least for the therapeutic aspect, a big part of HIV population, efficient comfort from these PLWHAs associations has been obtained.

In the three provinces where this research was conducted evidence revealed that the associations of PLWHA are a new phenomenon, where the members are looking for their own space in order to tackle the problem that is being posed by HIV/AIDS.

This research tried to disaggregate the experiences that are pertinent to these associations and give a voice to people in these associations. Most of the time, matters of HIV/AIDS have been ranked as least priority. This investigation of PLWHA associations which was conducted in three different geographical areas in the country showed more similarities than differences. These differences and similarities were within the association itself, the day to day running of the association, and the relationship of these associations with government institutions and civil society.

The study found three major modes of heterosexual transmission, transfusion and mother to child. The risk factors are: poverty, migration (miner), population movements, refugee return from countries with high HIV prevalence, high prevalence of STD in young people, resistance to condom use, economic dependence of women, and also lack of information, illiteracy and disbelief.

The research reveals, furthermore, that there are no significant differences between HIV/AIDS associations in these three provinces. There are more similarities than there are differences. They share in common unemployment, low level of schooling, uncontrolled urbanization, prostitution, lack of resources to support their family members, etc.). Other types of similarities are shaped by patterns of formation of these associations which were similar and may have been formed by the same people. However, in Maputo which is the capital city, due to the favourable conditions there, these associations and support groups are more developed and dynamic than in other provinces. It would however be interesting to find out how HIV/AIDS positive people in rural areas are responding to the problem of HIV/AIDS.

It is also worth remarking that HIV geographic distribution is uneven in the country. Central provinces (Manica, Tete, Sofala, and Zambezia) are more affected than the Northern and the Southern Provinces. The trends follow the major transport routes and the areas bordering Zimbabwe, Malawi and Zambia. In these areas of the country, many

factors, in the past, have contributed to increase HIV/AIDS infection and other are fuelling the spread of the epidemic (unemployment, low level of schooling, uncontrolled urbanization, prostitution, e.g.).

The study also found much variation or inequality between men and women around the issue of sexuality displayed by gender roles. For women and adolescent girls, the consequence of AIDS can be particularly dire. There is strong evidence, for example, that in African countries (e.g. Mozambique) women are often "blamed" for HIV disease even in circumstances where they have been infected by remaining faithful to their husband or other male partner. There is also evidence to suggest that women are less likely to receive the kind of care and support made available to male household members (Warwick et al., 1998). Moreover, where the male head of household has died there is sometimes loss of social support for young women, ostracization from the community, and lack of legal protection to inherit land and property.

The gender inequality is mainly confirmed by the reaction of men towards HIV test. It is said that when a woman is diagnosed with HIV/AIDS first, she does not get support from the husband or his family because the tendency is to blame her for contracting the disease and she may end up being returned to her parents. On the contrary, if the disease is detected first in the man, the wife will normally support him till his death even though she may be accused by her husband's family of bewitching the husband.

This study found that HIV positive women face difficulties when it comes to following the teachings of vertical transmission programmes because they lack the capacity to feed their babies with artificial milk. They feel obligated to breast feed their children because their families expect them to do so. In this regard, women are faced with difficult decision of disclosing their HIV status. On one hand, if they disclose their status they face the risk of being chased from home and, on the other hand, they face the risk of transmitting the virus to the baby if they breastfeed their child.

In Mozambique there are two different types of associations of people dealing with the problem of HIV/AIDS. These include support groups and PLWHA local association. Support groups are the informal groups that are not legally recognized by the Ministry of

Justice, while PLWHA associations are formal organizations and are legally recognized by the government. Nonetheless the objectives and most important activities are the same in both forms of organization. Most members joined the associations and support groups after being invited by the other members working as activists in hospitals.

This research argues, however, that lack of adequate knowledge about HIV/AIDS, fear of infection, the stigmatization, put these associations at a disadvantage in coming out to speak about their HIV/AIDS status and its associated problems.

This research accepts also the fact that members in these associations are firstly concerned with gaining material and financial support although sharing experiences and mutual consolation among members remain the ultimate goals. Most members of these associations are people who have HIV and are who lack economic means to have a better living. Therefore they are weak and have problems with performing their jobs.

The income-generating activities run by these associations are not sustainable because of stiff competition. There are too many NGOs doing the same income, generating activities making it too hard to market products produced. Another weakness is that they lack initiatives and the capacity to negotiate with donors for long term sustainable project.

The context of poverty, dependence, superstition, illiteracy, unemployment, violence and an overall sense of doom plays a role in sexuality and sexual and interplay amongst the poor, shaping their responses and, as shown in this thesis, their inability to protect themselves in the face of this pandemic. This highlights the fact that HIV/AIDS is a different reality for the rich and the poor people. In this regard, poor people in these associations do not have the means to support themselves and their families, while rich people have means to themselves and their families and can afford treatment in private clinics.

In Mozambique prominent citizens living with HIV keep their status hidden and are not involved in HIV/AIDS information awareness campaign in the associations of PLWA. This could be because of the fact that HIV/AIDS is seen as a disease for poor people. The

stigmatization of HIV/AIDS has become so high that people infected with the disease deny any association with this epidemic.

It was also realized that rich people experienced confidentiality with issues relating to HIV/AIDS when compared to poor people. This is because while poor people have to go the associations to deal with his/her reality, rich people have options of private clinics.

It should be added that poor members of PLWHA associations regard themselves as near death since they do not have access to antiretroviral drugs and other resources. They believe that their way of life changes after being diagnosed HIV positive they feel discriminated against and alienated by their families and their communities.

It was also discovered that most members of the associations did not disclose their HIV/AIDS status to their partners and families. They behaved as though they are not HIV positive and continued to have many partners. Women continue their reproductive cycles and breastfeeding despite attending the PTV Programa de Transmissao Vertical 'Transmitted Vertical Program' where they are through how to avoid the vertical transmission. The reason behind is that the fame of having a baby or being called mother of *xx* or *xy* (baby's name) is in Africa much more valued (even if the baby eventually dies later) rather than not having one.

This study showed that there are more women than men in PLWHA associations because women are found to have HIV/AIDS virus when they attend consultation related to their reproductive health. Women in these associations normally do not assume high positions and therefore it is difficult for them to address their major concerns. Men usually occupy executive positions. The traditional attitudes of gender inequality which consist in men always occupying dominant positions are reflected in the associations.

The research also showed that family members bear the burden of caring for the sick and their dependants and have the potential to do so even though they are sometimes failed by their limited resources. When a family member is HIV positive, it entails a high burden on his family because they have to support him/her under high level of poverty, increasing unemployment, deterioration of household income, and rising cost of living,

and poor coverage of health services. But there is sometimes little involvement of family members in the activities of PLWA associations due to lack of information. And some get interested only when their family members are about to start ARV treatment as required by PLWHA. Before a patient begins with his/her ARV treatment, a member of the family has to be briefed on the consequences of undertaking this treatment.

It is sad to remark that the increasing number of *GATVs* in the country is not accompanied by increasing level of knowledge of the HIV/AIDS pandemic. The number of people who undertake voluntary testing for HIV/AIDS is insignificant. Moreover, the only service provided is HIV/AIDS testing for people suspected of having the virus by the hospital.

Mozambique is passing through a difficult time in that beside the HIV/AIDS pandemic, the Government has to deal with other national issues which divert government attention on the problem of HIV/AIDS. In addition to the above, the adoption of the new liberal policy to reduce the intervention of the state in social welfare, health, and education impacts negatively on the fight against HIV/AIDS. Nonetheless the government does intervene on a small scale through the CNCS and the Ministry of Health. This is illustrated by increasing number of *GATVs*. The approval of antiretroviral policy is a good example of the interventions of government although many people also die from the treatment's side effects.

These findings revealed that the relationship within associations and between the various stakeholders is not always harmonious. Weak partnership among NGOs working in the field of HIV/AIDS, competitions for funding, and disagreements among the members of these associations are some of the problems that hinder the successful implementation of HIV/AIDS programmes. Most of the associations acknowledge that their organisations are weak and that; they lack human and financial resources to efficiently and effectively implement programmes. However the National networks of HIV/AIDS has made efforts in trying to solve this common problem jointly in the last few years.

Recommendations

On basis of the findings of this research, the author would like to make the following recommendations:

Given the fact that less than 1 % of People Living with HIV/AIDS in Mozambique are members of these associations, there is a need to do more work to integrate more people in these associations by mobilising people under VCT and, if they are found HIV positive, to encourage them to have access to associations, or perhaps even compel them to join as a condition for receiving ARV treatment.

HIV health care services and activities of PLWHA association should be extended to people affected with HIV/AIDS in the rural areas.

Government, civil society and the media should step up its efforts of reducing discrimination and stigmatization of PLWA through information campaigns. They should also redesign the messages in the information campaigns to ensure that they reach achieve the targeted audience, and add messages that promote PLWA associations and the benefits of joining them.

It is important to have a national welfare policy which will mitigate the problems of people infected and affected by HIV/AIDS. Particular attention should be paid to vulnerable groups like children who have been orphaned as a result of losing parents through HIV/AIDS. The government should take the responsibility of supporting HIV/AIDS positive women by providing milk and other food for their babies until they have grown up. Above all, reducing poverty should be one of the effective ways to deal with HIV/AIDS.

Prominent citizens in Mozambique should be mobilized to take an active role in the fight against HIV/AIDS. If they are infected they must come in the open and declare their status and get actively involved in the associations of people living with HIV/Aids in Mozambique. By doing this they will change the mentality of poor people who view AIDS as a disease for poor people.

NGOs and CBOs should strengthen their internal organizational structures and broaden their networks through forming partnership with other NGOs dealing with this issue. The increased efficiency in terms of service delivery and partnerships will strengthen their collective voice and make it easier for them to share resources, to work with other non-NGOs actors, and to lobby with the Ministry of Health Ministry and other institutions.

The author would like to call upon the government of Mozambique to increasingly involve PLWA in responding to the HIV/AIDS pandemic.

The government in conjunction with other stakeholders involved in the fight against HIV/AIDS should come up with a strategy that will encourage its citizen to undergo routine voluntary testing and counseling for HIV.

Government in conjunction with other stakeholders involved in the fight against HIV/AIDS should be more efficient and effective, thereby reducing the negative effects of bureaucracy. The government should mobilize more resources so that all HIV/AIDS infected people may have access to ARVs.

Given the challenges of the HIV/AIDS epidemic, the government and civil society need to pay attention to the plight of these families who usually have limited resources and are faced with the task of dealing with this problem.

The challenge of associations in Mozambique, therefore, is to recognize these weaknesses and to find means and strategies for overcoming them in order to reduce the impact of HIV/AIDS in the country.

Significance of Findings

These findings have significance for the discipline (anthropology) because they show that although much progress has been made to integrate HIV issues into our discipline, but much more still needs to be done. As a whole, anthropologists need to work much more effectively to produce, and publish more about HIV/AIDS. The findings also illustrate great differences between the creation and maintenance of PLWHA associations. There is a great discontentment from the members as regards to the management as they believe

that those in positions of power misuse the money. This money does not profit everybody. The author is of the opinion that this claim is worth consideration and that those engaged in business of HIV organizations need, and would consistently be, more concerned about the well-being of those whose rights and needs they claim to defend. A 'poor' quality service hosted by a business such as this one can generate immediate negative feedback from HIV people. If these poor people continue to express their dissatisfaction with services offered they may feel penalize both sides by the disease on the one hand and mentally and emotionally on the other hand.

Limitations and Future Research Opportunities

This study has hinted at a number of research areas which merit further study. In the area of retroviral treatment, it would be helpful for there to be an ongoing effort to evaluate whether this treatment helps or does not help Mozambicans. Researchers need to see on a continuing basis the side effects of these drugs. Another issue is that of structures that need to be put in place for HIV children or orphans left behind by parents who died with HIV to grow from with family love.

The idea of extended family that needs to be supported financially as they might wish to foster these children is a great idea but which requires further investigation. We think that PLWHA need to include such a project in its program as well. Surely there will be improvements and even greater improvements in the future if this project is given thought.

There should be additional research work to compare the PLWHAs operational, and informational enhancements of HIV education programs in urban areas with those operated by these organizations in the rural areas. The lack of knowledge or information in these rural areas demands it. Yet, the current research has illustrated areas in which the PLWHAs services are more advanced although it did not cover the whole country. Perhaps additional research work with larger populations would help in this regard.

There is clear evidence that PLWHA well-designed programs of sex education, which include messages about safer sex as well as those about abstinence, may delay the onset of sexual activity, and reduce the number of sexual partners, and increase contraceptive

use among those who are already sexually active). Here again, further ongoing research is warranted to see to what extent sex education's applications are important for HIV positive and negative people.

The current research has barely scratched the surface of what is obviously a concern of many international donor Institutions and NGOs. A reading of the written survey responses by our interviewees shows that there are clearly many financial problems related to mismanagement of PLWHAs or lack of transparency as far as the funds are concerned. A clear relationship has already been established between PLWHAs and their international donors on HIV issues; they must continue to build this relationship (foundation) so that it can save the lives of millions of people hit by the virus. How can the structure be altered as to meet the objects originally designed for the associations? This is the question that must constantly be asked and addressed to the stakeholders and more especially the leaders of the PLWHAs.

All these issues are important in a general sense in that their investigation will help us better explain our world and the people living with the virus. But the issues are critical to the future survival of the PLWHAs associations, which have themselves been threatened in many ways in the recent past. If we are to be the true researchers that Africa needs, we can possibly be in the research effort we make along these lines that must continue and be able to create effective strategies now to fight against HIV/aids in the years to come.

In short, the research effort was limited initially by a lack of theoretical development in the literature. Previous works did not provide enough linking materials on HIV to The case study of PLWHA, its creation and maintenance of its programs as evidenced by the interviews. While the methods used here are reliable, and the means of measurement appear valid, the concepts involved have not previously been investigated elsewhere and should be subject to further study.

This research was not intended to make claims about discussing the entirety of all the problems pertaining to HIV disease. Rather, the research was aimed at making generalizations about HIV as dealt with by PLWA associations in Mozambique, how they help those who are infected and affected by HIV. This research supports the work

that PLWHAs association do save lives of people. Whether PLWHAs have succeeded or not is another issue and the reader may draw his/her conclusions from the work.

Recommendation for further research

It could be important to find out how other HIV/AIDS positive people out of the associations follow the life of these associations. The institutions dealing with this issue have to investigate how they can work with other informal associations based in the communities and religions. To extend the study at level of rural areas, as a way to explore what the local institutions do in this context. Why these associations are only concentrated in the cities? As we live in the time where people migrate from rural areas to big cities in search of better opportunities of life will not be the cities invaded once more by HIV if considerable efforts are not made to contain the disease both in the cities and rural areas? Further studies are needed to explore all these areas. Above all as Monteiro suggest is important to accept the perceptions of multi voices approach in this matter of HIV/AIDS in Mozambique.

This study revealed that a number of significant socio- cultural factors had an impact on HIV/AIDS situation in the three provinces. But it didn't gather evidence showing how these different factors impact in HIV/AIDS context. For instance data from INS Instituto Nacional de Estatistica ' National Institute of statistic' concerning to HIV/AIDS prevalence in the three regions of the country, indicate that the Northern Region has a low level of prevalence. It may be important to undertake a study in this region where Muslims are predominant.

It would also be interesting to find out why other HIV/AIDS positive people are not members of these associations dealing with the problem informally and not through associations, for example at household level, community level, church level etc.

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Appendix

(1) List of Acronyms and Abbreviations

AIDS- Acquired Immune Deficiency Syndrome

AMODEFA- Associacao Mocambicana do Desenvolvimento da Familia

CBOs- Community Base Organizations

CEA-UEM- Centro de Estudos Mocambicanos Universidade Eduardo Mondlane

CNCS- Conselho Nacional de Combate ao SIDA

FDA- Food and Drug Administration

FDC- Foundation for Development of the Community

Frelimo- Front of National Liberation Movement

GATV- Services of Counseling and Voluntary Testing

GTZ- German Technical Cooperation

HIV- Human Immunodeficiency Virus

ICW- International Community of Women Living with HIV/AIDS

INE- National Institut of Statistic

Kindlimuka- A National Organization of People Living with HIV/AIDS

MISAU- Mozambican Ministry of Health

MONASO- Mozambican Network of AIDS Service Organization

MPT1- Medium Term Plan

MSF- Medicos sem Fronteiras

MULEIDE- Mulher Lei e Desenvolvimento

NACP- National AIDS Control Program

NAPWA- National Association of People with AIDS in South Africa

NGOs Non Governmental Organizations

NPCS- Provincial Nucleon Against AIDS

PLWHA- People Living With HIV/AIDS

PLWA- People Living with AIDS

PMA- World program for Food

PNUD- Programa das Nacoes Unidas para o Desenvolvimento

PVOs- Private Voluntary Organizations

RENAMO- Movement of National Resistance

RENSIDA- National Network of Associations of People Living with HIV/AIDS in Mozambique

SAT- Southern Africa AIDS Training

SIDA- AIDS

STI- Sexual Transmitted Disease

TARV- Ante Retroviral Therapy

TASO- The AIDS Support Organization in Uganda

UNAIDS- United Nations Agency for AIDS

UNDP- United National Development Progr am

UNDP- United Nations for Development program

UNICEF- United Nations Children's Fund

USAID- United States Agency for International Development

VTC- voluntary Counseling and Testing

WHO- World Health Organization

WLWA- Women Living with AIDS

Guide of the interviews for the different target group

Specific questions directed to members of the board of the associations

Here major emphasis was put on understanding the many issues that can be divided into 3 sections, as follows:

- What has motivated the creation of the associations? Who, how and when they were created?
- How do they do function?
- What type of structure do they have?

The way members adhere to the associations as well as the membership requirements; member's rights (benefits) and obligations; their funding sources; the way associations interact,

Both in the country and outside.

- Difficulties encountered (relationship among members and with other members of the civil society, governmental institutions and financial support).

PLWHA who are members of the associations

Concerning this target group, it's maybe also important to find out what actually motivates people to join those associations.

- In what circumstances and how do they learn about the association's existence and mission?
- Why do people become member?
- What are the advantages and disadvantages in being a member of such kind of association?

- Do they receive some kind of advice?
- Are their family members aware of their individual membership status towards the associations?
- How do their family and other members of society in general react to this situation?

Officers of the local and international NGO's dealing directly with these associations:

- When did they start working jointly with these associations?
- What kind of partnership do they develop with these associations?
- Do they develop specific activities? What kind?
- What are their impressions about PLWHA's associations?
- What are their major difficulties in dealing with the associations?
- Apart from these associations, which other partners do they have?
- What are the differences between the associations?

Governmental institution's representatives working with the associations

It is perhaps important to get to know the government's position towards matters related to People Living with HIV/AIDS in the country, because they are the most important decision-making bodies. It seems also relevant to find out the kind of strategies they draw on in dealing with the HIV/AIDS pandemic, particularly with people already suffering from AIDS. Questions including:

- What kind of support do they give to the associations?

- What are the challenges being taken by the government towards minimizing the impact of the disease?

What type of activities do they develop in these contexts?

